

## Active social citizenship: the case of disabled peoples' rights to personal assistance

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Personal assistance is a welfare scheme that aims at increasing disabled peoples' independence and empowerment. Since the historical beginnings of this scheme, rights have played a crucial role, but are rarely analysed per se. This article presents a social scientific analysis of personal assistance legislation in the Scandinavian countries. Based on a theoretical framework focusing on variations of the concept 'active citizenship', it discusses the complex balance between the strength of rights and activation requirements, whether explicitly or implicitly expressed in the legislation. This article concludes that Sweden combines a strong right with implicit requirements, while Denmark and particularly Norway combine a weak right to personal assistance with rather explicit requirements that must be met in order to be eligible for the services. This article is a contribution to the discussion, originally introduced by T.H. Marshall, on how to strengthen peoples' 'membership of society' through social rights.

**Keywords:** personal assistance; citizenship; social rights

### Introduction

Currently, ideas about empowering welfare service users and emphasizing their role as active citizens, in regard to their services, as well as within society, are pillars of the changing European welfare states. This includes the Scandinavian countries which are in focus here. However, although rights (as presented in legislation) are an important tool for safeguarding these ideas, they are rarely the focus of analysis. In this article, we will discuss the case of social rights regarding personal assistance (PA). PA is a rather small but crucial welfare arrangement within the long-term care sector. It is explicitly described as a service encouraging disabled peoples' empowerment and increasing their options for being active in their lives (see the introduction article by Askheim, Bengtsson, and Richter Bjelke 2013). The international history of PA for disabled people is rooted in the US independent living movement of the 1960s, and was inspired by the civil rights perspective of the time (cf. e.g. Oliver 1990). However, in the growing literature regarding the PA scheme, for example, in Scandinavia, the legislation is discussed only as a part of a country's welfare history (see e.g. Bjelke Jensen and Evans 2005 (DK), Andersen

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et al. 2006 (N), Larsson 2008, and Egard 2011 (S)). It is rarely the legislation per se – from a social science point of view – that is the focus of discussion. This includes the very few analyses within international literature addressing directly disabled peoples' rights regarding community care services (see Rummery 2002), and analysing the practice regarding whether these services are accessible and can contribute to disabled peoples' option of being members of society. This article is a contribution to filling this gap in the literature.

Theoretically, our discussion is related to both classic and contemporary analyses of citizenship. The concept of citizenship is strongly tied to the power relationship between the state and the individual. This relationship, in turn, is crucial to peoples' rights to welfare services. The roots of this discussion go back to T.H. Marshall (1950) and his analysis of the development of citizenship during modern times. Marshall points to 'social citizenship' developed in the twentieth century and includes in this individual rights towards the state regarding a minimum standard of life, welfare and security. The theories of Marshall have been criticized, in particular by feminists who claim that Marshall's citizenship concept does not include all people. Taking into account this critique and also the fact that newer social processes in society, such as the much discussed process of individualization, have since taken place, we elaborate on a contemporary Nordic approach to social citizenship, which points to the new emphasis on active citizenship. Here, citizens' duties, self-responsibility and participation regarding welfare services are 'mixed together at the same time or in relation to the same individual' (Johansson and Hvinden 2007, 15). As indicated by this quote, this 'activation' contains different ideological and political variants. Johansson and Hvinden clarify these variants by using the activation-differentiation developed by Miller (2000), which comprises a socioliberal interpretation (duties in return for PA), a libertarian (stressing self-responsibility) and a republican one (stressing participation). This differentiation model will be central in our theoretical framework and will be applied in this article's analysis to identify variations and trends of activation ideas in PA legislation.

This article consists of three parts. In the first part, we will explore the theoretical and analytical framework further including a suggestion of how to 'operationalize' the concept of rights as a basis for discussing the strengths of a right and its activation requirements. In the second part, we will apply this framework in the analysis of each of the Scandinavian countries, using as our key material PA legislation text including relevant preparatory work, as well as guidelines (see the attachment list). Our discussion is based on a text analysis of this legislation material. This analysis is shaped as a qualitative document analysis (Scott 1990), where we describe what we find is the material's answers to our questions and thereby clarify the status of PA rights in each country. Simultaneously, we search for empirical content (explicit and implicit) related to the concept of 'activation' in each country's legislation material. We present a comparative analysis emphasizing differences between 'similar cases' (Ragin 1987), as the Scandinavian countries utilize the same type of welfare regime; the Nordic social democratic type, focuses on independence of the market and family for citizens, and stresses safety in regard to people's need for help in everyday life (Esping-Andersen 1999). The third part further explores the analysis of differences by providing an overview and discussion of the various intra- and inter-country differences we uncovered.

### **Exploring rights and citizenship**

Rights are ambiguous and difficult to define, and even if some rights are considered as social rights, they are not always given to those who need them (c.f. e.g. Hollander 1995; Åström 2005). While this more comprehensive examination of putting the legislation into practice is not included in our discussion, the legal right is, here for PA. A right can be both ethical and legal (NE 2012), but our discussion is confined to the legal right based on legislation. Legal rights represent a subgroup of human rights, and are defined as basic rights that individuals can demand from the state or municipalities (Fisher 2001). Human rights are universal, but they are reflected in national law and are part of different kinds of international agreements. In this context, the concept of (the state's) duty is of central importance. For example, Hydén (2002) points out that an agreement – like a convention – becomes legally binding when states explicitly declare themselves bound by them.

The purpose of the UN convention on rights for persons with disabilities (2006) 'is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedom by all persons with disabilities and to promote respect for their inherent dignity' (UN Convention, article 1). Among the general principles of this convention, and of specific relevance here, is that the convention requires 'full and effective participation and inclusion in society' (UN Convention). One significant article from the convention is no. 19: 'Living independently and being included in the community'. This article states that disabled people should have access to a range of in-home, residential and other community support services, including personal assistance in order to prevent isolation and segregation. In other words, the convention sets ambitious targets for the social inclusion of disabled people.

The Scandinavian countries have adapted to the UN regulations in varying degrees. Sweden has ratified both the convention and the protocol. Denmark has ratified only the convention, while Norway had signed it, and only recently (June 2013) ratified it. PA plays an important role in meeting the ambitious convention targets. Interestingly, this overall varied Scandinavian picture is mirrored in how it has been legislated. While Sweden has a separate law for PA, Denmark, on the other hand, has included PA in a more comprehensive law regarding social services, and Norway has gone even further by incorporating it into a law including both health and social services (see below). Both Norway and Denmark, in contrast to Sweden, thereby treat PA rather as an alternative to traditional welfare services like home help. This differentiation brings into the discussion the strength of a right; we will mention here two points regarding this. One is that, in order to be a strong right for the users, it is essential that the right is clearly specified in law (Hollander 1995; Hohfeld 1964[1919]). However, we will show that even though this basically is the case with PA legislation in Scandinavia, it does not prevent the law (text) from including strong requirements for the user. The other point is that, to be a strong legal right, the right should be a claim of right for the user (if the citizen desires PA it will be provided to her/him) and it should be associated with an obligation for some other party (Hohfeld 1964[1919]). In the case of PA, the other party is the municipality, as it is a municipal responsibility to implement PA in Scandinavia. In all three countries, the municipalities are obliged to offer PA to their residents, to assess the volume of PA, to reassess the help on a regular basis and to involve the user in these processes. However, this does not necessarily imply a claim of right for the resident, and, furthermore, activation requirements can be important conditions for the rights.

The basic discussion here concerns the individual state relationship and, thereby, the classic, Marshall-introduced discussion of citizenship. Marshall's theories generally concern the development of citizenship over time, but a part of these theories that is particularly relevant to our discussion is his special interest in the impact on social class, which can also be looked at as the impact on inequality. In fact, citizenship, in Marshall's view, is a principle of equality (Marshall 1950, 33), and the modern impetus for the development of citizenship is social equality. Social rights, including PA, therefore historically follows the development of civil rights first (rights necessary for individual freedom, such as freedom of speech, thought and faith, and including rights to justice), and later political rights (rights to contribute to political power) (Marshall 1950, 10–11). Important to each of these rights – or, more precisely, elements of citizenship – are the institutions (within the state) they are connected to, which in the case of social rights, and relevant here are the social services (more broadly speaking, the welfare state). In other words, the welfare state is committed to enabling social rights. And, based on the idea of the impact of citizenship on social inequality, Marshall treats citizenship as 'a status bestowed on those who are full members of a community' (Marshall 1950, 28), and following this stresses directly that 'All who possess the status are equal with respect to the rights and duties with which the status is endowed'. In line with a range of feminists (see e.g. Lister 1997; Yuval-Davis 1997), we oppose Marshall's analysis for including only men (his discussion of the fulfillment of contribution to the society was confined to those in paid work or military service, excluding thereby also disabled people) and for using a liberal-inspired strong demarcation line between the public and private sphere. Yet, the key elements of our discussion fundamentally relate to Marshall's classic contribution to the discussion of citizenship. These key elements are about equality, membership of society, and the inclusion of both rights and duties (the historical order being duties and rights, see Marshall 1950), and they are the basis for the questions this article raises: In which sense is PA a social right in Scandinavia? What kinds of rights and duties, in terms of activation elements are built into the PA legislation, including changes? And what kind of contribution does the Scandinavian PA legislation make to the basic discussion of disabled peoples' 'membership of society'?

### **Active citizenship – self-responsibility, self-determination and mutual duties**

Basically, 'active citizenship' is the antithesis of an active state (Oskarsdottir 2007). This means the state's responsibility is somehow reduced. Although the rhetoric can be about 'empowering the users', a stimulus for this reduction can be the high costs that welfare states, and in particular the Scandinavian ones, have faced in relation to their generous welfare schemes (see OECD 2005, 26). Central to our discussion here is that the pressure towards activation can be motivated by left wing, right wing and/or third way policies, even simultaneously. This is in fact the situation within the welfare state today, and it is expressed in the literature by the general discussions of the changing welfare state as affected by, and meeting challenges from above (globalization, Europeanization etc.), as well as changes from below, from people showing an increasing awareness of their rights (Johansson and Hvinden 2007, 6). In order to include these different but simultaneously existing trends here, David Miller's differentiation of social citizenship into a libertarian, a republican and a socioliberal variant is relevant (Miller 2000). While the individual state relationship

in the socioliberal version involves mutual rights and obligations, in the libertarian one it involves self-responsibility and individual autonomy. The republican variant focuses on the citizen's participation in her/his community, with the goal of strengthening the community through this participation. The difference, then, between this republican variant and the socioliberal one is that the latter is more paternalistic in its approach. In other words, while the libertarian variant places most of the responsibility on the user, the socioliberal places the responsibility on the state, while the republican variant holds a position in between them.

One way of using Miller's theories as an analytical tool for discussing activation is to define what is 'active' and what is 'passive' in each of the three variants (see Johansson and Hvinden 2007, 44). For example, the principle of 'receiving' services is considered a passive aspect of the socioliberal variant, and the help to self-help principle, a passive aspect of the republican variant. In contrast to this, we will not focus on 'passive' aspects, but instead will consider the three variants as activation-variations that, in turn, comprises a strong emphasis on duties in return for PA services (socioliberal), self-responsibility for organizing PA (libertarian), or self-determination of one's own life in order to take an active part in society through work, education and/or social events (republican). In other words, these activation variations include different political tools to push the activation of citizens in different directions. However, and this is important here, the different variants can be mixed in the (legislation) texts, which then makes it crucial to identify the elements that are pushing an activation-variant. Regarding the usual positive connotation of calling something 'active', one should be aware here of the different political affiliations of activation.

Based on the theoretical issues and the intention of comparing (in this article's third part) differences in 'similar cases', we will now present each country's analysis using the following questions for structuring the discussion: (1) What is the intention of the legislation covering the PA? (2) Who is the target group (excluding who)? (3) What kind of activation requirements is included? and (4) What sort of access is there to complain about the municipal decision? Based on the answers to these questions, we will determine the direction in which each country is moving, in relation to active citizenship.

### **Sweden – a claim of right combined with libertarian activation?**

The regulation of PA in Sweden is divided into two acts: the act (1993: 387) which concerns support and service for people with certain functional impairments (LSS), and the act concerning the assistance compensation (LASS) (now regulated in the Social Security Code 2010:110). Both acts were implemented in 1994. LASS specifically regulates the right to state assistance benefits and the calculation thereof. LSS is a supplementary law to the Social Service Act from 2001 [1982]. It states that 'The goal of the act is to make the individual able to live like others' (5 §) and that 'The arrangement should be based on respect for the individual's self-determination and integrity' (6 §). While this seems to build on a republican idea of participation, the law text simultaneously stresses (in this context) a libertarian idea of making the services 'strengthen the[ir] ability to live an independent life' (7 §). The preparatory work (prop. 1992/1993:159) explicitly states these elements too. PA is probably the most important part of the LSS regarding the opportunities to study, work, have a

family, be politically active and participate in community. But this is framed by restrictions and requirements related to the target group.

When LSS replaced the former Act of Special Services, it simultaneously enlarged the target group, but this does not mean there are no restrictions. The target group for PA is described in LSS as including three groups, consisting of (1) persons with learning disabilities, (2) persons with considerable intellectual disabilities, and (3) persons with other major and permanent disabilities, which cause considerable need for support and services (see also the policy article by Storgaard Bonfils and Askheim 2013). While a diagnosis gives a right to PA for groups 1 and 2, the third group is required to have needs which are long-lasting and not related to disability caused by a normal process of ageing. In all three groups the needs should appear before the age of 65, which implies an exclusion of people aged 65 and older (prop. 1992/93159). In 2001, this was made less restrictive by letting those aged 65, who were already allocated PA, to continue with their services (prop. 2000/01:5).

In addition to the above-mentioned criteria, it is required that basic needs are met by the services, specified in LSS 9 a § as ‘... personal modelled services given to a limited number of individuals who, because of major and permanent disabilities, need help with personal hygiene, meals, dressing and undressing, communication with other people and other kinds of help that requires thorough knowledge about disabled people (basic needs)’. The user entitled to PA can choose either to get PA or financial assistance (care services or cash); the latter in terms of reasonable expenses for the required PA. This direct payment then implies that the individual takes more responsibility. The user can choose to arrange his/her assistance on his/her own, thereby being a self-employer (employing one’s own personal assistants). However, if the individual does not want this, the municipality is obliged, based on the user’s decision, to organize municipally managed assistance. Also, the user can alternatively choose a cooperative or private company to provide this support. But it is important here to notice that it is not a requirement to take on the employer or manager role, as long as the user is assessed as belonging to one of the PA’s target groups.

Seen in the light of which people the target groups comprise, a surprisingly strong activation requirement exists in regard to the application before allocation. The law text states that the services should ‘only be given to the individual if he or she requests it’ (LSS, 8 §). It is the individual who shall ask and apply for PA from either the municipality or from the insurance fund (see below), if the basic needs surpass 20 hours a week. Only in exceptional cases can the application for PA be made by parents or a legal guardian or representative (LSS 8 §).

Social Services and The Swedish Social Insurance Agency are the institutions dealing with the allocation. If the application is turned down there is a right to appeal to the higher court. This provides a control function, which is also exercised by the National Board of Health and Welfare. The laws regulating PA are the most complex in the social insurance system, because they require a high degree of cooperation between different local authorities, and involve interpretation and implementation issues (Bengtsson and Gynnerstedt 2003).

### **The Swedish rights and activation variant**

The Swedish PA legislation is designed as a claim of right according to Hohfeld’s description (1964[1919]). PA is clearly expressed in the LSS legislation, and the target groups are also identified in the text. This means that when a person with disability is

considered to belong to one of the three target groups and is under 65, and also considered to need assistance with basic needs in her/his daily life, needs that are not met by other public sources or, for example, by family, the individual has a right to PA. This right is based on an obligation for the municipality to provide help. The municipality cannot propose any other operation or refuse the application on the grounds that there are no resources for it. The individual, furthermore, has the opportunity to appeal to the Administrative Tribunal if s/he is dissatisfied with the decision. The court then examines both the legality and the aptitude of the decision and has the power to change the decision (Clevesköld, Lundgren and Thunved 2012). No explicit demands, in terms of activation, are required of the individual who is receiving PA, except from the expectation that PA will strengthen an independent's life after the allocation has taken place.

However, a strong activation requirement is placed prior to the allocation process, which means it operates rather implicitly. It concerns the process of obtaining PA. In this process, the individual must apply independently for PA, a diagnosis must be shown and the person must demonstrate the need for help. In other words, although Sweden has a claim of right to PA, it simultaneously requires the user to take over the responsibility of applying for PA in the first place. We interpret this as a libertarian activation requirement, clearly dominating the direction despite some republican ideas included in the law text. Also, we find that this libertarian activation direction, in the Swedish case, is strengthened by the option, given to the users by law, of choosing PA (when in the target group), and, further, by the option of choosing direct payments, as these options encourage becoming a self-employer, as well as organizing the assistance on one's own.

### **Denmark – a right to be assessed combined with libertarian socioliberal activation?**

In Denmark, PA is part of the Social Services Act, first implemented in 1998. The intention according to this broader law is to 'encourage the individual's possibilities of managing on his/her own or to ease the individual's life . . .' and 'The help is based on the individual's responsibility for her/himself and her/his family. The help is organized on the basis of the individual person's needs and conditions and in cooperation with the individual'. (§ 1, Stk. 2 and 3, published 08.02.2011). Except for the republican idea of involving the user, the main inherent idea in this intention is libertarian as it emphasizes self-responsibility.

The Danish PA scheme is included in the Social Services Act §§ 95 and 96. § 95 gives the municipality the option of giving the citizen a cash payment as an *alternative* to §§ 83 and 84 about traditional services (personal and practical help or relief), *if* the municipality is not able to provide the help that is needed. In other words, this option is referring to a state of emergency and it should cover only traditional home services. § 96 is different, as it is about PA directly; it has required the municipality to offer PA, called 'Citizen controlled personal assistance' (Borgerstyrt Personlig Assistance, BPA) since 2008 (Law no. 549). Although this is also about cash payments, it represents a specific type of help that targets maintaining 'an independent life with the possibility of participating in social life', according to the guidelines for BPA (15.02.11:6).

The target group of § 95 regarding cash payment comprises those who have considerable and permanent physical or intellectual disability, and need more than 20 hours of help in their home per week (cf. §§ 83 and 84). § 96 changes this target group

to those who are physically or intellectually disabled and who have needs that make it necessary to provide this special form of help (Social Services Act, 08.02.11:18). This implies that BPA can also be provided to disabled people with a need for less than 20 hours of help, if the municipality determines that they require coherent and holistic help (Stk. 3). However, basically § 96 is for disabled people with comprehensive and ‘special’ needs in terms of seeking independence. The difference between § 95 and § 96 is mirrored in the fact that the average number of hours of help used per week is 41 and 109, respectively, according to a survey (Nordisk Felagsmalaraduneyti 2009). It is the user’s own choice whether she/he wishes to receive BPA (Guidelines 15.02.11:2). But it is the municipality that makes the decision whether someone is entitled to BPA (Guidelines by DUKH, February 2011), which is indeed very different from the Swedish case. §§ 95 and 96 have neither an age limit nor require certain types of disability. However, there are several important activation requirements (§ 95 Stk.4, § 96 Stk. 2, according to the guideline 15.02.11: 3–4).

One activation requirement is that the user must be able to function as the manager of her/his service providers, here called ‘helpers’. This management role includes working out schedules, making job descriptions, performing interviews, providing training on a daily basis and carrying out personnel meetings. Another requirement is that the user should also take over the functions of an employer, on her/his own or with the help of a relative, association or private company. The tasks included here are to hire/fire helpers, write employment certificates, do payslips (this can also be done by the municipality or a private company/organization) and take into account environmental arrangements (according to the Danish working environment act). The municipality then has to make sure that the user is provided the necessary instructions. We interpret this as a mutual exchange of chores and duties.

People in Denmark who are denied BPA, because they are considered as being unable to function as managers, unsatisfied with getting traditional services instead of BPA, or find that they have not got the volume of help they need, have a right to complain. The complaint goes to the Social Board of the central government (Det Sociale Nævn i statsforvaltningen). Prior to this, the citizens had the right to get a written explanation for the decision they are unhappy with, including guidelines for complaining.

### **The Danish rights and activation variant**

The Danish variant gives disabled people no full claim of right to PA, but rather a right to be assessed, to receive an explanation and to complain. The municipality’s obligation is about providing help, but not necessarily BPA. If, on the other hand, BPA is seen as the best solution, then the disabled person finally gets in the position to freely choose, in a libertarian sense, whether she/he wants BPA or not, and how to manage the employer role. However, if she/he chooses it, she/he then has to fulfil certain activation duties in return for receiving BPA, and only some can be carried out by others.

We find that Denmark sends a combination of libertarian and socioliberal signals through its legislation. The libertarian ones are primarily expressed through the emphasis on self-responsibility in the purpose of the law and the option given to people for receiving cash payments. The special history of PA in Denmark holds an important influence over this aspect of the policy. The history goes back to the first ‘Århus-arrangement’, which required disabled people eligible for cash payments to be

very active in their daily lifestyle (Bjelke Jensen and Evans 2005). This requirement was steered by the present law guidance (not the law text), and was later included in the Social Services Act of 1998. Important to this context is that this high level of activity obviously first reflected a life practice among disabled people with PA. However, when it was included in the law's wording it was transformed into an activation requirement, or more precisely a 'duty' in the socioliberal variant of activity, thereby excluding certain people from the target group for BPA. Today, this duty is dismissed (Guidance for BPA, from 24.02.11: 6). However, as mentioned above, the law now includes other duties in terms of coping with the manager role and possibly the employer role as well. These are duties performed clearly in return for being provided with BPA. The requirements necessitate resources not possessed by many disabled people who could be included in the target group for BPA. Consequently, the relevant duties represent a further restriction of the target group, although there is a possibility of handing over employer tasks to another party based on the freedom of employer choice. Looking at the overall direction of the old and new requirements, the ideas of self-responsibility have remained strong in shaping the Danish case.

#### **Norway – a right to be assessed combined with socioliberal activation?**

In Norway, PA, called 'User controlled personal assistance' (Brukerstyrt Personlig Assistanse, BPA), was first enacted in the Social Services Act in 2000 (Lov om sosiale tjenester m.v.). The general intention of this act was 'to contribute to increased equality and prevent social problems, to ensure that each individual has the opportunity to live independently and to have an active and meaningful life in community with others'. Since 1 January 2012, the Social Service Act has been replaced by the more comprehensive Municipal Health and Care Services Act (Lov om kommunale helse- og omsorgstjenester). In addition to incorporating the intention of the Social Service Act mentioned above, the intentions of the Health Care and Services Act include, additionally, the prevention, treatment and facilitation of coping with illness, injury and/or disability. We find that the goal of the act is mainly based on republican ideas of self-determination of one's own life and participation in society with others.

The Municipal Health and Care Service Act § 3–8 states that the municipality must offer BPA in terms of practical assistance and training, organized as user-controlled personal assistance. Since the beginning, the Norwegian BPA has been described as 'an alternative organization of practical and personal help for people with comprehensive disabilities with need for assistance in their daily life, both within and outside their own homes' (Ot.prp. No. 8 1999–2000:1). It is thereby emphasized that the arrangement should be seen in combination with other municipal services.

The target group comprises users who have complex and comprehensive needs, are able to act as managers of the scheme, and have the resources to live an active life within and outside their home (see also Storgaard Bonfils and Askheim 2013). Until 2006, the decisive criterion to qualify for PA was the user's ability to act as a manager for her/his assistants. This was a strong duty, in a socioliberal sense, in return for social benefits in terms of PA. From 2006, PA was extended to persons who are not able to act as managers of the arrangement on their own, for example, people with intellectual impairments and families with disabled children (Rundskriv I-15/2005). In those cases, another person will be manager on behalf of or together with the service

user, for example, a relative. This is a significant extension of the target group. Yet, there is still a strong requirement of management capacity, if not taken over by the user, then by another person. Of importance here is that the municipality is seen as the party that has the competence to assess whether the user/relative/guardian is able to act as a manager of BPA. Therefore, although this is a situation where the state takes a step back and transfers more responsibility to the user, it is handled in too paternalistic a fashion to represent a libertarian idea, and it actually extends the target group. We therefore interpret it as pointing in the socioliberal direction instead.

The Ministry of Social and Health prepared a circular on BPA which provided guidelines to the municipalities as implementing agencies (Rundskriv I-20/2000). This circular is still in use, even though there is a new act since January 2012. The circular says, on the one hand, that the municipalities are obliged to offer BPA in their repertoire of social services. On the other hand, it further states that the municipality has the competence to decide which services are the most appropriate for the individual user. Similar to the Danish case, the municipality makes the decision about whether someone is entitled to BPA; it is not a claim of right as in Sweden. The municipality makes a decision, and this decision sets the framework for the practical assistance offered as BPA. The municipality then assesses the amount of help which should be at 'an acceptable level', according to the guidelines. However, there is a general clause on user participation included in the Patient and User Rights Act § 3-1. It states that the services, as far as possible, should be designed in cooperation with the user. The design of the care services, including BPA, should emphasize the user's opinion of the services offered. This expresses a republican goal of user participation.

The BPA user in Norway has the right to appeal to the County Governor (Fylkesmannen) if the application for BPA is rejected or if the user experiences that the allocation of hours is too low. The municipality's decision may be set aside by the County Governor after appeal if it seems unreasonable or contrary to the law. The municipality has the competence to decide who should be the employer of the PA model: whether it should be the municipality itself, a private organization or the user. However, this is not part of the administrative law-based decision and it is not an individual decision either. Thus, the user has no right to complain about who the employer will be, but only about a rejection or an insufficient allocation of hours.

### **The Norwegian rights and activation variant**

The Norwegian BPA gives disabled people the right to be assessed for PA and to complain if they are not satisfied with the solution. The municipality is obliged to provide social services, but not necessarily BPA. However, if the municipality sees BPA as the best solution for the user, she/he can choose this service.

Our analysis shows that Norway represents, overall, the strongest socioliberal case of the three countries because of five intersecting reasons. Firstly, there is no separate law for BPA as it is integrated in the Health and Care Services Act. Secondly, BPA is always seen in relation to other public services when assessed and allocated based on legislation, and it is regarded as an alternative to other services. Thirdly, the decision of whether someone is eligible for BPA is clearly up to the municipality, and so is the decision about who the employer should be. Fourthly, the duties of BPA users are strong and explicit, although it is possible to get help with the employer role. And finally, BPA in Norway is less often a question of cash payment

than in Sweden or Denmark. Together these characteristics point at the Norwegian case as being based on a strong mutual exchange of chores and duties, and from the perspective of disabled people as rights in return for duties.

### **Discussion of Scandinavian activation in PA legislation**

Although we have not made it a part of the country's analyses above, we additionally find that all three countries – on a general level based on legislation and guidelines – include in their PA schemes republican ideas in terms of requiring the user to participate in the application and allocation of PA, with some variations when practiced. This discovery of republican manifestation has not been included in our analysis because it lies outside the legislation text to give detailed directions for the process concerning application and allocation. On a general level, the republican variant is evident in the Swedish model in the expectation for the user to take part in the decision process regarding their needs (possibly related to a diagnosis). However, a new national general assessment policy was implemented in 2011 by the officials in the Social Insurance Agencies. And because this assessment protocol (*Behovsbedömningsstödet*) is very detailed, it signals a restriction of the republican negotiation idea. In Denmark and Norway, there is a similar republican idea of 'cooperation with the individual' and this is taken even further in Norway through emphasis on a dialogue. However, the decision process that lead to the allocation of the Danish and Norwegian BPA seems to have been weakened again, because municipalities are encouraged to use the detailed system called 'the method of functional ability' (*Funksjonsevnetmetoden*) in Denmark, and the method of assessment called *IPLoS* (see Christensen 2012) in Norway. Correspondent across the Scandinavian countries is that these new systems for the concrete assessment of peoples' needs are standardized and very detailed, and therefore lead rather to more municipal control than to more user influence on the decisions regarding PA. In this sense, the republican element instead creates a skin influence, in other words, an influence without substance.

Based on our legislation analysis and the ambiguous republican signals found, our analysis in general shows that all three Scandinavian countries mix different activation types (for an overview, see [Table 1](#)). But we still find it possible to indicate a direction for future development, although this is sometimes mixed. This is the case with Denmark in particular, which is moving in a mixed libertarian–socioliberal direction. We also find that a country's direction is related to the strength of the country's specific PA right. As Sweden has established a strong right in terms of a claim of right giving people the option of choosing PA if they want – as long as they belong to one of the target groups – the activation requirements in terms of duties are less relevant. This might also be an explanation as to why there is a particular Swedish emphasis on self-responsibility regarding the application of PA. In other words, you have a right to PA, but it is your own responsibility to claim it. As this requirement takes place prior to the PA allocation process, it is rather implicit. Furthermore, although the target groups are defined, the definitions raise questions of interpretation, and thereby also contain possibilities of implicit exclusions which are hard to button down. The combination of a claim of right and a libertarian direction of activation policy is principally a paradox, but that is exactly why the Swedish case can reveal that a full state responsibility can still include implicit and strong requirements for the users.

Table 1. Overview of Scandinavian PA legislation in terms of the type of right and activation.

Right type			
Activation type	Libertarian	Republican	Socioliberal
Sweden Claim of right	Self-responsibility for applying for PA The option of choice of PA when in the target group The option of choice of cash payments or services	The intention of strengthening self-determination, in particular through user cooperation, but confined by 2011 assessment system (“behovsbedömningsstödet”)	
Denmark Right to be assessed	The intention of strengthening self-responsibility Cash payments The history of “high activity level in life style”	The intention of strengthening self-determination, in particular through user cooperation, but confined by a standardized method (“funktionssevne-metoden”)	Certain duties in terms of requirement of manager- and employer-capacity in return for PA
Norway Right to be assessed		The intention of strengthening self-determination and user participation, in particular through user cooperation in terms of a dialogue, but confined by IPLOS	Duties in terms of requirement of manager and employer capacity in return for PA

Denmark and Norway, contrary to Sweden, have no claim of right, only a right for people to be assessed for PA. In Norway, inspired by the Swedish case, the Ministry of Health and Care issued a Green Paper in 2007. This report proposed that PA should be authorized as an individual claim of right for disabled people in need of extensive services, which means more than 20 hours a week (Helse- og omsorgsdepartementet 2007). Furthermore, the ministry proposed that the users should have the right to decide who should have the employer role. So far this proposal has not been adopted by the Parliament. However, the Parliament came up with a proposal in June 2011 which will make ‘PA a right for disabled people with great need for services, within the same economic framework as today’ (Soc. Dem. 2012). The Norwegian Directorate of Health has the responsibility to investigate and report on this in an upcoming proposal next year. The interpretation of whether disabled people are below or above the required 20 hours will then be crucial in the Norwegian case, and most likely turn into an implicit type of activation requirement similar to the one discovered by Sweden. If Norway adopts the policy of cases of needing over 20 hours leading to a claim of right to PA, it will also be crucial whether the republican idea of a dialogue with the user – which we find is strongest in the Norwegian case – will be maintained, or whether this will be modified significantly by the standardized assessment system, IPLOS.

Denmark represents, so far, the ‘in-between’ case and seems to combine its historical libertarian practice with newer socioliberal inspired ideas about mutual

duties. In particular, the Danish case shows how complex the balance is between self-responsibility and duties in return for services. The Danish case also illustrates the danger of institutionalizing practice, leading to exclusion risks through activation requirements rather than inclusion of more disabled people benefiting from the scheme.

## Conclusion

In Scandinavian countries, PA represents a social right – in an expanded sense of Marshall’s original interpretation – because the countries have a legislation that is meant to cover disabled peoples’ vital needs for assistance caused by physical or intellectual disability, either directly through PA or in combination with other public services and help from others, for example, relatives. We have found that while the Swedish claim of right is joined to a more implicit activation requirement, the Danish and Norwegian right to be assessed implies more explicit activation requirements. PA is a welfare scheme that takes its point of departure from the idea of empowering disabled people in their everyday lives, in order to minimize the barriers for them to live like non-disabled people. In this sense it fits very well with Marshall’s (1950) original idea – when enhanced here to include disabled people – about social rights enabling a ‘membership of society’ and thereby strengthening social equality. However, it basically also represents a republican idea encouraging participation through self-determination. In this perspective, it has a ‘swinging’ risk between requiring self-responsibility on one side and active fulfilling of duties on the other. As the Scandinavian countries have taken a world lead regarding public responsibility for welfare schemes, it is particularly important to raise awareness of and avoid the encouragement of the self-responsibility side. Our analysis of PA legislation is a contribution to this Scandinavian commitment.

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