Democracy and Design in Swedish Personal Assistance

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Abstract

The present study investigated the role of personal assistance service providers for people with disabilities from the users' point of view. Interviews with 12 users resulted in five value categories: (1) Interact with the user in a service-minded way (2) Have a proper ideology of personal assistance, (3) Mediate between users and personal assistants, (4) Provide good work conditions for personal assistants and (5) Represent the user politically. This study illustrates that classical theoretical models of customer service might be less suitable to explain the role of service providers for Swedish users of personal assistance. In order to provide successful service and support, service providers might need to consider interactions beyond the provider and the end-users, and also include issues such as political lobbying, working conditions for social workers and sustainability in terms of guaranteeing the service in the future. The findings are discussed in relation to service management theories and the service design society.

KEYWORDS: service provider, personal assistance, people with disability, personally designed support

Introduction

Personal assistance is a personally designed support for people with disabilities who need assistance with basic needs such as personal hygiene, meals, dressing and communication. For most users, personal assistance is designed in co-creation between the service provider, personal assistant(s) and the user (SOU 2005:100). The aim of the present study is to explore what users desire of their service providers of personal assistance, and how the assistance could be improved. Qualitative interviews were held with 12 users of personal assistance to find out what their personal needs are and how these might be met by service providers.

Swedish personal assistance – A personally designed support to people with disabilities

The Swedish system of personal assistance is designed to support people with various disabilities. The Swedish system is more generous, in respect to governmental funding of

assistance (per user), than the systems in the United States and the United Kingdom as well as other systems in Scandinavia. If the criterion of basic needs is fulfilled, the person may also receive personal assistance with a wide range of tasks in working life, family life, leisure activities, cleaning and many other areas (Grönvik, 2007; Selander, 2015). The Swedish system also gives the users much more influence and control over the assistance received than any other system (Askheim, 1999, 2005). The user can decide to arrange the assistance by employing assistants her-/himself; requesting assistance through the municipality; forming an association or co-operative with other users; using another company or organization or by both employing assistants her- /himself and receiving assistance through the municipality or another service provider (Swedish Social Insurance Agency, 2007). The present study focuses on users who delegate the employer's liability of personal assistants to a service provider (>96% of the users).

Three kinds of service providers

There are three different kinds of service providers; public (i.e. municipality), user-cooperatives and private firms. For simplicity, we can view the user as a customer who receives a check from the government for which he/she can buy the assistance he/she desires (Norén, 2000). All service providers are formal employers of their assistants. They are responsible for legally regulated working conditions, such as work environment and sick leave. In general they also manage financial administration and recruitment of personal assistants (Norén, 2000). The basic difference between different kinds of service providers is the view of personal assistance. Personal assistance for public service providers is about providing personal assistants who can execute different kind of tasks for the user. Cooperatives and private firms on the other hand, prefer to delegate as many tasks as possible to the users. Salary and education for personal assistants are centralized for public providers while they usually are decentralized to the specific user in the case of a cooperative or a private firm (Norén, 2000). Users who arranged their personal assistance through public providers have less influence and self-determination over the people working as personal assistants and the tasks they assign. Users with user-cooperatives had the most influence to decide on their personal assistants (Calleman, 2008). There are no legal formalities concerning what should be included in the work or a service provider and there are no legal barriers to enter the market. Instead of providing obligations, the parliament encourages service providers to listen to the desires of their specific users and independently tailor-make their *personal* assistance. This implies that the quality standards among different service providers might be slightly different and sometimes contradictory (Hugemark & Mannerfelt, 2003).

Research objective

For users with a service provider (>96% of the users) personal assistance is designed in co-creation between the service provider, personal assistant(s) and the user (SOU 2005:100). However, the roles of the actors in designing the service usually differ across the municipality, user-cooperatives and private firms. The aim of the present study is to explore what users desire of their service providers of personal assistance, regardless of the variation in the frame factors related to specific instructions. To improve services designed for people with disabilities, researchers must first ask people with disabilities what they desire from specific services. Regarding support and services for people with disabilities, decisions are many times taken by politicians without including the people the decisions concern (Gough, 1994; Söder, 1995; Lutz & Bowers, 2005). It is hoped that this study will contribute to a more democratic service design practice, foremost in the field of vulnerable users. It is worth noticing that this study focuses on desires of service providers of personal assistance, not desires of personal assistants themselves.

Method

The research design is qualitative interviews with 12 users. The interviews have been analyzed through content analyze.

Participants

An invitation to participate in an interview was sent to 311 users, who were randomly selected from the total population of 474 users who received personal assistance for basic needs for at least 20 hours a week in the area of Gothenburg in Sweden. A total of 31 users consented to participate and among them 12 interview persons were selected in order to include a variety of users as regards age, gender, service provider and impairment. The final sample consisted of 12 adult users, four male and eight female. They ranged in age from 21 to 65 (mean age 47 years). Three users had public service providers, four users had user-cooperatives as service providers and five users had private firms as service providers. The time during which they had been users of personal assistance ranged from 1 year and 11 months to 11 years and 9 months (mean time was 7 years and 10 months). The number of assistant hours per week ranged from 40 hours to 224 hours (mean 118 hours per week).

Interviews

A qualitative interview was conducted as an everyday conversation in which the user was encouraged to talk freely (Mishler, 1986). The interview started with an overarching question: "In your opinion, what does the concept personal assistance imply?" More focused questions were; "what are important characteristic features of a service provider of personal assistance?", "what is characteristic of a bad service provider?", "what is characteristic of a good service provider?", "do you find your service provider lacking in any way?", "how do you perceive quality concerning a service provider of personal assistance?". This type of questions invites participation and narration. The questions overlapped and were only brought up if the free conversation did not cover them. We also asked the users to give examples of characteristics of bad and good service providers from their own experiences. Further, we asked the users who had changed service providers (n=9) if the change was related to a specific incident. Such incidents are sometimes referred to as critical incidents, and can be described as incidents that make significant contributions – in this case negative – to an activity or phenomenon (Bitner, Booms & Standfield Tetreault, 1990). The interview lasted between 45 and 80 minutes. The interviews were audio recorded and transcribed verbatim before the analysis.

Content analysis

Both qualitative and quantitative content analysis was used to analyze the interview texts (Krippendorff, 1980; Berg, 2004 and Schilling, 2006). The text was first divided into meaning units; transcribed verbal expressions whose content corresponded to what the user desires of their service provider. Each meaning unit was then condensed to its basic content by deleting all unnecessary linguistic expressions and transforming its content into a short form (Schilling, 2006). Thereafter, the condensed meaning units were coded and similar codes were grouped together into categories. The development of categories was derived through a bottom-up process; from inductive inference concerning coded, condensed meaning units (Smith, 2003; Berg, 2004). We created 19 sub-categories through the questions; "what attribute desirable of a service provider is this code about?", "what other codes are about this desire?" and "what distinguished codes in this category from codes in other categories?". The last step in our analysis was to order the 19 sub-categories into five categories, based on a bottom-up process (Graneheim & Lundman, 2004). Since the narratives yielded rich and complex information, the categories are illustrated using representative interview quotations (Smith, 2003). In order to offer the reader an idea of how salient the categories are, we have also used a quantitative content analysis in order to count the number of users falling within each of the 19 sub-categories (Smith, 2003; Berg, 2004).

Ethical considerations

Nine users were able to give informed consent to participate in the study themselves. In three cases, the users gave informed consent through legal guardians. Before the user (or legal guardians) consented to participate, all contacts between the researchers and the user were meditated by the Swedish Social Insurance Administration.

Results

The analysis of the results revealed 19 sub-categories of user-values related to service providers. Those 19 attributes were possible to cluster in five categories; (1) interaction with the user in a service-minded way (2) having a proper ideology of personal assistance, (3) mediating between users and personal assistants, (4) providing good working conditions for personal assistants, (5) representing the user politically.

The categories are illustrated in figure 1. Table 1 shows the categories, the sub-categories and their frequencies.
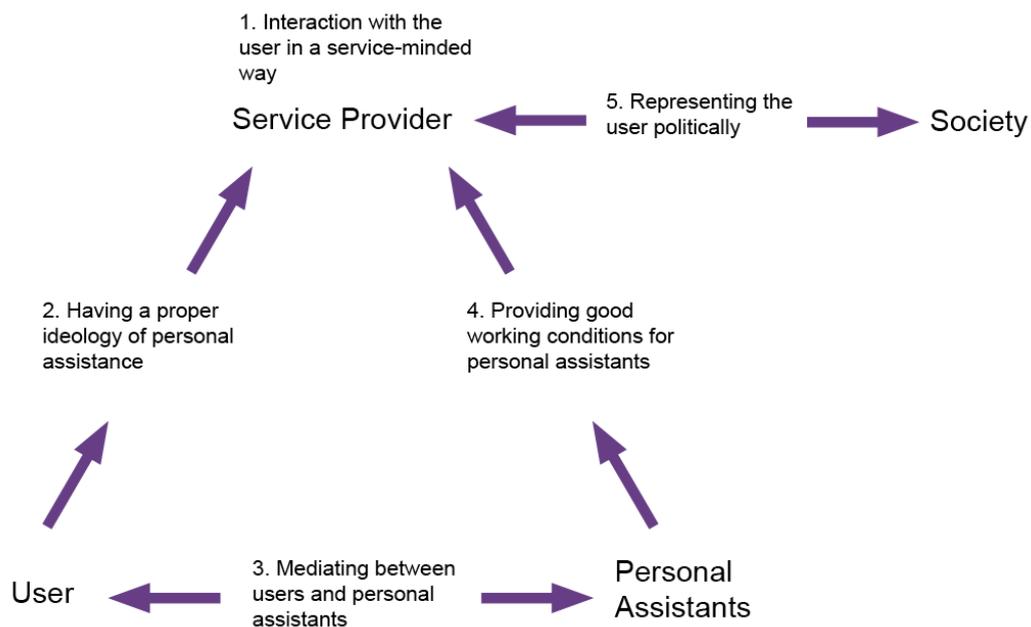

Figure 1. **Matrix of actors and five categories of desired attributes of service providers from the perspective of the user.**

Table 1

Categories of values that people with disabilities desire from their service providers

1.   Interacting with the user in a service-minded way: (n=12 i.e. all users)

    1.   Empowering the user: (n=6)

    2.   Caring about the user: (n=8)

    3.   Supporting the user when the user asks for a favour: (n=6)

    4.   Reducing the user's workload related to personal assistants: (n=2)

    5.   Providing assistants in all situations: (n=3)

    6.   Providing a limited number of assistants to the specific user: (n=1)

    7.   Arranging training for users/legal guardians: (n=1)

    8.   Arranging social activities for users: (n=3)

    9.   Covering extra costs related to personal assistants: (n=2)

2.   Having a proper ideology of personal assistance: (n=7)

    10.   Following the legal framework of personal assistance: (n=4)

    11.   Having the user's well-being as first priority: (n=2)

    12.   Personalized support and service: (n=5)

3.   Mediating between users and personal assistants: (n=7)

    13.   Arranging meetings: (n=3)

    14.   Handling conflicts between the user and the assistants: (n=5)

4.   Providing good working conditions for personal assistants: (n=8)

    15.   Arranging training for personal assistants: (n=4)

    16.   Providing good administrative conditions of employment for assistants: (n=3)

    17.   Arranging supervision for personal assistants: (n=3)

    18.   Providing instrumental rules and instructions for personal assistants: (n=2)

5.   Representing the user politically: (n=2)

    19.   Being politically engaged on the behalf of the user: (n=2)

Note. The figure after each category and sub-category (n=#) refers to the number of users falling into this category.

Interacting with the user in a service-minded way

Nine attributes describe how the users would like their service providers to interact with them in a service-minded way;

Empowering the user (table 1:1)
The users would like to be given more control over their assistance by the service provider representatives. In order to have a level of self-determination, the user would like the service provider to give clear and timely information about things such as the recruiting process of new assistants. The user would also like to be kept informed as to whether an assistant is unable to work, and also receive an open account of the assistance money, in order to plan activities for her-/himself and her/his assistants. In order to empower the user it is important that the representatives of the service provider regard the user as an equal human being who is responsible and reflective. One user, who only has a physical disability, has noted that representatives of service providers feel they must confront verbal users:

> *I can feel that my service provider has a disparaging attitude toward the users. A lot of users have a handicap which prevents them from expressing their desires and experiences. My handicap is only physical, which means that the service provider views me as a fusspot who can speak for myself.*

A representative of a service provider who does not empower the user views the user as a person who should be controlled and looked after. A woman with an intellectual disability describes a situation when the representative took over too much, as follows:

> *The representative of the service provider forced me to sign a paper, stating that the assistants can stop me from eating food which is not mixed and ground, because I am not able to chew. But instead of explaining in a normal way, the person just put the paper on the desk and tapped the dotted line twice. "Sign it, you have to sign it", the person said, instead of explaining what it was about.*

The users state that the service provider should listen more to the users and recruit more representatives who are receivers of assistance themselves, in order to better understand the user's perspective of empowerment. This would allow for a more democratic and user-friendly design of the assistance system.

Caring about the user (2)
It is important for users to feel that representatives of the service provider cares about them and takes an active interest in their wellbeing. For example, representatives might make efforts to have a dialogue and a personal relationship with the user (e.g. through home visits, telephone calls, etc). Such a person pays attention to the user's specific needs and takes initiatives to satisfy them. One user put it like this:

> *If it were not for a home visit by a contact person of my service provider, I would not have this wheelchair. The person saw my old model and informed me about a more modern and suitable wheelchair.*

A user who felt that the representatives of the service provider did not care enough on a personal level described it in the following way:

> *In the past, a representative of my service provider always passed by with a present for Christmas, which in itself is very nice. But last Christmas, the service provider sent the present and seasonal greetings through a personal assistant. I would like the contact person to wish me a Merry Christmas her- or himself, at least on the telephone. It is neither about the present nor the seasonal greetings. It is about being treated as a valuable person, that you are somebody. I feel sorry for my service provider, that they do not understand better.*

Specially designed training programs for new personal assistants and service provider representatives could help ensure empathetic responses to assistance users and their needs, as well as create company policies for relationship building so that these initiatives do not have to come from individuals, and so that contact with users holds a consistent standard in order to manage expectations.

Supporting the user when the user asks for a favour (3)
Users state that in order for them to receive effective support, the service provider must be available and provide representatives that are both motivated and competent. Being available is a necessary condition to serve the user on demand. A motivated representative of the service provider acts seriously and sympathetically when the user, for one reason or another, asks for a favour. One user had bad experiences with an unmotivated representative:

> *I desired support to advertise for a new assistant at the homepage of my service provider. The service provider was not motivated to support me, she gave an unclear description of how to advertise instead of practical support. The ideology of my service provider is to delegate as many tasks as possible to the user, but despite this ideology, I think my service provider should have been more helpful, when I, on this single occasion, asked for a favour.*

A service provider might offer expertise such as legal assistance and simple medical care to their users. They might also support the user in potential conflicts with the Swedish Social Insurance Agency concerning the number of assistance hours or if a personal assistant suffers an accident while working.

Reducing the user's workload related to personal assistants (4)
The users would like their service providers to reduce the workload related to personal assistants, for example in the recruiting process of new assistants and support during different meetings with assistants. One user describes this reduction of his workload in the first step of the recruiting process of a new assistant in the following way:

> *The first step is important, if they only send me trash [incompetent potential personal assistants] in the first step, they give me the whole workload in the recruiting process. That is wrong. I am the disabled person. I have less force to recruit assistants than a healthy person. Furthermore, they are not paying me for such a workload. They are not paying me at all. The payment I receive is in the form of good assistance.*

Providing assistants in all situations (5)
It is important that the service provider is able to provide assistants that suit all situations (e.g. all times, all places and all activities). Some users need assistance during the night. One user states: "I changed service provider because the organization could not guarantee assistants during the night."

Some users also live in distant places or might want to embark on an activity suddenly (e.g. go to their summer house or take a drive), it is important that the provider can offer appropriate assistants at short notice. In some cases it is also necessary to provide two assistants at the same time.

Providing a limited number of assistants to the specific user (6)
The service provider should provide a limited number of assistants that serve a specific user in order to establish a good relationship between the user and the assistants. One woman explains: "I have 23 different personal assistants, because my service provider distributes them to all users. It is terrible not to know who is working tomorrow morning".

Arranging training for users/legal guardians (7)
Users desire training for the purpose of improving their relations with their personal assistants. For users with legal guardians, the service providers could arrange training for the guardians so that they can represent the user in a better way.

Arranging social activities for users (8)
The users would like their service providers to arrange social activities for them, such as Christmas buffets, journeys, meetings and parties. Such activities make it possible for users to come together and have fun with other users.

Covering extra costs related to personal assistants (9)
The user would like their service provider to cover the extra costs for personal assistants. Extra costs of personal assistants can be related to consumer goods (e.g. coffee, toilet paper, soup etc.) or to durable goods (e.g. an extra chair for assistants). The service provider should guarantee such goods automatically, as one user said:

> *When I need something [that is related to the consumption of personal assistants], representatives of the service provider should pass by and give me that, such as kitchen paper, coffee and serviettes.*

Having a proper ideology of personal assistance

Users of personal assistance explain that it is important that their service providers have a clear ideology of what personal assistance is and how they should practice personal assistance:

> *The service provider should not practice assistance by coincidence. They should know what they are doing. They must have an ideology which is deeply rooted in the whole organization.*

The ideology of personal assistance goes beyond specific actions. The service provider's ideology of personal assistance must be built on the legal framework of personal assistance and the well-being of the user. However, it is not enough that the service provider has the user's well-being as first priority. The service provider's ideology of well-being of users should also correspond to the specific user's ideology of well-being for her-/himself. In other words, the assistance should be adapted to the needs of the specific user. Designing a system for creating personalized care plans could benefit users. According to the users, a proper ideology of personal assistance should follow these three attributes:

Following the legal framework of personal assistance (10)
The service provider must follow the governmental instructions about what personal assistance is and what tasks are included in the assistant's work. According to some users, their provider lacks knowledge of legal rules related to irregular working hours for assistants, expenses for user's travels and extra assistant costs. Several respondents highlight the importance of distinguishing personal assistance, which is regulated in the "Assistance Benefit Act", from home help service, which is regulated in "The Social Service Act":

The service provider must know the "Assistance Benefit Act"; too often they confuse the "Social Service Act" with the "Assistance Benefit Act". The difference between the two acts is particularly large as regards the standard of living for people with disabilities; the "Social Service Act" refers to a reasonable standard of living while the "Assistance Benefit Act" refers to a good standard of living.

Having the user's well-being as first priority (11)
The service provider representative should be aware of the high stakes for the user and prioritize the well-being of the user instead. One user states:

The most important thing is that a service provider has a clear understanding of what personal assistance is and how important it is for all users. It is a reform, which could be gone tomorrow. You have to treat it with that in mind. You can't just take the assistance money and go to the Bahamas, jeopardizing the entire reform. You just don't do that. What is difficult for people [people without disability] to understand is that a careless act on the part of the service provider representative will only lead to that particular person being fined or sanction in some other way, whereas the life of all the users will be ruined. The difference is enormous.

A threat to the well-being of the users is profit-maximization. Users would like their service providers to have a different ideology than general business organizations:

When greed exists, the assistance becomes businesslike. Greed in the form of money and materialism disturbs the order, it is not humanitarian anymore. The service becomes worse and the service provider attracts the wrong kind of assistants.

Personalized support and service (12)
According to the users, it is difficult for one service provider to give high quality assistance to all the different users. Therefore, the service provider should adjust their ideology to serve a particular segment of users, for instance users with brain injuries or only physical disabilities. From an ideological point of view, segmentation is the beginning to personalized support and service, which might facilitate the empowering processes.

Mediating between users and personal assistants

The users would like the service provider to mediate between the user and the assistant throughout. The users want personal meetings as preventive measures to keep up a good relationship between themselves and their assistants, while they would prefer that the service provider handles conflicts if the relationship with the assistant is not satisfactory. Two sub-categories describe how this might work;

Arranging meetings (13)
The service provider should take initiatives to arrange personal meetings in which the assistants and the user (and possibly a legal guardian) participate. Some users would also like their providers to invite other concerned people to the meeting (e.g. physiotherapists and occupational therapists).

Handling conflicts between the user and the assistants (14)
It is important that the service provider act as soon as it knows about a conflict between the user and the assistant. One user described the providers' role in handling a conflict as follows: "I have neither the strength nor the desire to handle a conflict between me and my assistants. It shouldn't be up to me, it is the service provider who should look after their staff".

Some conflicts are related to different opinions between the user and the assistant, for example considering what should be included in the assistant's work. Other conflicts are related to specific occasions in the user's everyday life, for instance if the assistant breaks something and refuses to put it right. To know about a conflict, the service provider must be sensitive to what is going on between the user and the assistants. The users desire an easy way (e.g. a contact person), both for themselves and their assistants, to inform the service provider about a conflict. Wishes concerning how conflicts should be handled vary between different users. Some users would like the provider to speak with the user and the assistants separately first, and then arrange a joint meeting, while some users would like their service provider to arrange a joint meeting from the beginning.

Providing good working conditions for personal assistants

Four sub-categories describing what the users would like the service provider to do for their personal assistants;

Arranging training for personal assistants (15)
Users desire that the service providers should arrange different kinds of courses for their assistants. Such courses can be of a more theoretical character in order to inform the assistants what assistance is about. Desired courses can also be related to more practical tasks such as lifting techniques and cooking.

Providing good administrative conditions of employment for personal assistants (16)
Service providers who offer good employment conditions for their personal assistants, with decent monthly salaries and proper leave entitlement, are deemed better by users. The service provider should also transfer the salaries in a proper way. If the service provider offers good conditions for their assistants, the assistants will stay for a longer period of time and provide better assistance. As one user stated:

> *The service provider must have good conditions for the assistants. The provider should be afraid of loosing them. Everything that contributes to the dissatisfaction of the assistants will also influence me. If the assistants are not pleased, they can quit working here. They must be pleased so they like to come to my home and work.*

Arranging supervision for personal assistants (17)
Supervision for personal assistants can be given on a regular or temporary basis. Regular supervision is given through recurrent meetings and works like a "sounding board" for personal assistants. Such support strengthens the relationship between the service provider and the assistant and is arranged in order to improve everyday communication between them. Temporary supervision is usually given as emotional counselling to relieve the pressure on the assistant during a critical period of time. One user describes a situation where she wanted the service provider to give the assistants better support:

> *During the autumn I have felt very low. I have quarrelled with the medical service, I have quit all social activities, I even thought that I did not want to live anymore. The situation must have been frightful for my assistants. It must have been terrible for the assistants to be in such an environment. During this critical period, the service provider should have given support to my assistants, because I was not strong enough to give them sufficient support.*

Supervision can either be given to each assistant independently or simultaneously to all assistants.

Providing instrumental rules and instructions for personal assistants (18)
The user perceives the "Assistant Benefit Act" as unclear considering the job description of personal assistants. Therefore the users would like their service provider to clearly set rules for what the assistants are allowed to do and not to do. One user stated:

> *I would like the service provider to have more rules for personal assistants. I have heard that they [personal assistants] sometimes carry paving stones in the garden. The service provider must clarify what you can expect from your personal assistants.*

Representing the user politically

Some users would like their service provider to not only act in relation to specific users and assistants. They would like their provider to act in relation to the society and represent the user politically.

Being politically engaged on the behalf of the user (19)
The service provider should defend the institution of personal assistance at a political level and prevent economical reductions related to personal assistance. One user describes political achievements as follows:

> *I would like the service provider to work close to the government and the parliament and try to prevent reductions related to personal assistance. The service provider should fight for the rights of people with disabilities. It is hard for the user and the user's family to fight for the user's right.*

The user would also like their service providers to keep them updated about what is happening with personal assistance on the political level.

Discussions

Beyond the basic customer perspective of service providers

The user of Swedish personal assistance is sometimes regarded as a customer in a service market (Norén, 2000; Hugemark & Wahlström, 2002; Hugemark & Mannerfelt, 2003). According to Gummesson (1994, 1998), four basic interactions determine the quality of the service provider from the customer's perspective; (1) the interaction between the service provider's contact personnel and the customer, (2) the interaction between the service provider's systems and the customer, (3) the interaction between the service provider's physical products and the customer and (4) the customer-to-customer interaction. According to us, the main difference between the general service customer and the user of personal assistance is that the user desires attributes beyond the direct interaction between her-/himself and her/his service provider. Service design from the perspective of the user in this study is more complex than service design from the classical perspective of Gummesson (1994). The complexity is related to the close relationship and close human interactions between user and provider, and the democratic intention of Swedish personal assistance to provide user freedom and empowerment, rather than to governmental rules and regulations.

According to Laswell (1951), the benefits of positive aid for people with disabilities are "to overcome handicaps that would otherwise prevent the achieving of a full human experience" (Laswell, 1951, p. 477). Even if we do not agree with the concepts "aid" and "handicaps", we nevertheless think that the benefit of personal assistance must be to develop the user toward her/his full human experience. In traditional service production, the customers enter the stage during the production process and are therefore integrated in a value-added process. The interaction is sometimes extremely intense and intimate and includes enormous stakes for the customer. The more intense and long-lasting the relationship between the customer and the service provider is, the more flexible the service provider must be to adapt the service to the customer-specific desires (Grönroos, 2007). In personal assistance, the customer not only enters the stage during the production process, he/she typically also stays in the production process for a life-time in order to achieve her/his full human experience. Therefore, the service provider must offer tailored support to the individual's needs. But in order to provide equality and justice between users and also for not jeopardize the support and service in a long term perspective, the users understand that the service design of personal assistance need to take more aspects into account than the service production through the interaction between themselves and their service providers.

Recommendations and practical implications

In line with previous research (Holliday, Ward, Awang & Harson, 2014) our recommendation is to involve a range of stakeholders, including end-users, personal assistants, service provider representatives and politicians, in co-creation sessions in order to better design support and services to people with disabilities. We hope that different kind of stakeholders can learn from the user-driven insights presented in this paper and thereby help to improve the quality of support and services to people with disabilities. This study highlights some priority areas for service design in the era of Swedish personal assistance; such as clearness in judicial instructions of what service and support is included in personal assistance, transparency of the service provider´s internal and external work, efficient routines to follow-up support and services, social interactions beyond instrumental exchange. As stated in the beginning, personal assistance for people with disabilities is more generous in Sweden than elsewhere. However, we believe that deep user insights from the welfare state of Sweden can be useful for designing services for people with disabilities also in societies with less state support and thereby contribute to democratic service design practices also outside Sweden.

Benefits for the service design community

The underlying idea within Swedish personal assistance is to create value for users by tailoring support and service to the specific needs of individual users, so that they may live their lives as other citizens do. As stated in the introduction, a user might receive support for basic needs and for other needs if criteria for such basic needs are fulfilled. However, neither basic needs nor other needs are clearly defined or regulated in any governmental documents or acts. Therefore, there are no clear specifications of what should be included in personal assistance or what the assistance money should be used for. A tailor-made support without a ceiling regarding needs might have some problems, especially as there have been no barriers to entering the assistance market for service providers. As a consequence, the costs of Swedish personal assistance have been far higher than expected. As is clear from this study, a lot of users worry about the future of personal assistance and would like service providers to consider more service interactions in society. Further, they want their service provider to pay a lot of attention to ethics and politics in their raison de être, rather than business related goals (e.g. service-mindedness and profit maximization).

When it comes to service and support to people with disabilities, decisions are many times made by politicians without including users. When the service is too free and financed by the government, the Swedish lesson of personal assistance has showed that costs run surprisingly fast. Studies like this one open up new questions about service design, which is quite a new industry that still is trying to define itself and its value. This study unearths challenges that are complex, personal, often tied to individual people's behavior but that also touch on fundamental values in our society. We know that service design is a great way to tackle challenges but this specific case requires a deep and mature methodology with strong ethics. There are several of these types of cases in society that come with large risks and responsibilities, not just to current users and caregivers but to the whole system. As already mentioned, it is hoped that this study will contribute to a more democratic service design practice, foremost in the field of vulnerable users. This goal might be attained in at least three ways.

1. User insights from this study might directly guide service providers in their support to people with disabilities, benefiting users and the industry as a whole.
2. The user insights might guide politicians to clearly decide and explicitly specify what should be included personal assistance support, in order to both guarantee the equality in support across users and to reduce the running costs while still providing quality assistance.
3. The insights can open up a larger discussion within the service design community about understanding the responsibilities and consequences of working with societal services that cater to vulnerable users. This is clearly a sector that could benefit from a service design

perspective, yet also one that will require deep and delicate handling by service design professionals.

We suggest that the discussion of what should be included in the work of not only assistance service providers, but all such governmental services, starts from the users´ perspective, as presented here.

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