QUALITY OF PERSONAL ASSISTANCE

Shaped by governments, markets and corporations

John Magnus Roos

Department of Psychology

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Abstract

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Background: Swedish personal assistance for people with severe disabilities became a legal right in 1994. The support is completely financed by the government and with a few exceptions transferred to External assistance providers (EAPs). There are three types of EAP; the municipality (i.e. public providers), private firms and user-cooperatives. An EAP is the formal employer of the user's personal assistants and supports the user with a wide range of services. Different EAPs have different perspectives on personal assistance, different legal frameworks and different raisons d'être.

Aims: The thesis has three aims; (1) to explore what users desire of their personal assistance i.e. their EAPs and their personal assistants, (2) to compare user-satisfaction across different EAPs, and (3) to compare the number of assistance hours between users of different EAPs.

Participants: Adult users in the area of Gothenburg who received personal assistance for basic needs (e.g. hygiene, meals, dressing, communication) for at least 20 hours a week, and who arrange their personal assistance through an EAP.

Methods: Three different research methods were used in the thesis; (1) qualitative interviews with 12 users, in order to explore what users desires of their personal assistance, (2) survey study of 427 users (response rate 39.3 %) in order to compare user-satisfaction across different EAPs, and (3) register data from the Swedish Social Insurance Agency in order to compare number of assistance hours across users with different EAPs.

Results: Users would like their assistants to be obedient, reliable, informative, alert, respectful, considerate, friendly, pleased and practical. Users would like their EAPs to have a "proper" (well thought through) ideology of personal assistance, interacting with the user in a service-minded way, mediating between users and personal assistants, providing good working conditions for personal assistants and representing the user politically. In 2008, users of personal assistance were more satisfied with other EAPs (i.e. private firms and user-cooperatives) than municipal providers. During the period 1994 – 2006, an average user with a private firm had received 18.4 percent more assistance hours than an average user with a municipal provider.

Key words: Personal assistance, public reform, customer satisfaction, service quality

John Magnus Roos, Department of Psychology, University of Gothenburg, Box 500, SE-405 30, Göteborg, Sweden. Phone: +46 31 786 1641. Fax: +46 31 786 4628. E-mail: magnus.roos@psy.gu.se.

Preface

This thesis is based on the following four studies, which are referred to by roman numerals:

I. Roos, J. M., Hjelmquist, E., & Thorén-Jönsson, A-L. (2009). *What do people with disabilities desire from their personal assistants?* Unpublished manuscript.

II. Roos, J. M., Thorén-Jönsson, A-L., & Hjelmquist, E. (2009). *What do people with disabilities desire from their service organisations of personal assistance?* Unpublished manuscript.

III. Roos, J. M., & Hjelmquist, E. (2009). *Arranging home-based personal assistance through private or public service providers: How satisfied are consumers?* Unpublished manuscript.

IV. Roos, J. M., Hjelmquist, E., & Steen-Carlsson, K. (2009). *Swedish personal assistance; provided according to needs or according to service provider?* Unpublished manuscript.

POPULÄRVETENSKAPLIG SVENSK SAMMANFATTNING

Brukare av personlig assistans i Göteborgs kommun är mer tillfredsställda med det stöd som alternativa anordnare (privata bolag och brukarkooperativ) erbjuder än det stöd som kommunen erbjuder. Samtidigt har samhällets kostnader (staten via Försäkringskassan) varit avsevärt högre för den privata assistanslösningen (privata bolag) än för den kommunala.

I februari 1993 konstaterade regeringen att socialtjänstens och hälso- och sjukvårdslagens insatser för personer med funktionshinder var otillräckliga. I syfte att förbättra levnadsförhållandena för människor med funktionshinder infördes år 1994 rätten till personlig assistans för personer med stora och varaktiga funktionshinder, och som vid ansökningstillfället inte fyllt 65 år. Personlig assiststans ges för att klara grundläggande behov som måltider, personlig hygien, kommunikation med andra samt annan hjälp som förutsätter ingående kunskap om personen med funktionshinder.

Finansiering och organisation av personlig assistans skiljer sig i viktiga avseenden från andra samhällsstöd, exempelvis hemtjänst. Personer som beviljats personlig assistans (brukare) kan överlåta det formella arbetsgivaransvaret på kommunen, brukarkooperativ eller privata bolag. Försäkringskassan betalar ut ett visst belopp per beviljad assistanstimme. Förenklat skulle man kunna säga att brukaren får en check av staten med vars hjälp han/hon kan köpa den assistans som önskas.

Sedan assistansreformens införande har de privata bolagens marknadsandelar kontinuerligt ökat på kommunens bekostnad, medan brukarkooperativen har legat kvar på en konstant nivå. År 2007 var den svenska marknaden uppdelad enligt följande; kommunen 55%, privata bolag 30% och brukarkooperativ 11% (övriga 4% bestod av brukare som själva var arbetsgivare, samt brukare med okänd anordnare).

Den grundläggande skillnaden mellan kommunen och de alternativa assistsansanordnarna (privata bolag och brukarkooperativ) är synen på personlig assistans. För kommunen handlar frågan främst om att tillhandahålla assistenter som kan utföra vissa uppgifter åt människor med funktionshinder. För de alternativa anordnarna är inställningen att delegera så många uppgifter som möjligt till brukarna. För kommunen bestäms lön och utbildning för personliga assistenter centralt, av en kommunal tjänsteman. För de alternativa assistansanordnarna är det vanligt att lön och utbildning bestäms av den specifika brukaren.

Statens kostnader för personlig assistans har ökat kraftigt sedan reformen infördes. Denna ökning förklaras främst utifrån att antalet brukare har ökat och att antalet assistsanstimmar per brukare har ökat. Vid reformens införande uppskattades 7000 personer vara i behov av personlig assistans mer än 20 timmar per vecka. Vidare uppskattades medelbrukaren vara i behov av 66 assistanstimmar per vecka. År 2007 konstaterades att ungefär 15000 personer i Sverige hade assistans mer än 20 timmar per vecka och genomsnittet var 106 assistanstimmar per brukare och vecka.

I avhandlingen analyseras brukares tillfredsställelse och samhällets kostnader för olika assistansanordnare. Avhandlingen är uppdelad i fyra studier.

De två första studierna kartlägger vad brukare tycker är viktigt i stödet personlig assistans. Utifrån 12 intervjuer med brukare i två kommuner i Västsverige analyseras vad brukare efterfrågar från sina personliga assistenter (studie I) och assistansanordnare (studie II). Resultaten i studie I visar att brukare efterfrågar följande kvalitetsaspekter hos en personlig assistent; diskret, lydig, pålitlig, informativ, redo, respektfull, omtänksam, vänskaplig, tillfreds (med sig själv, sitt arbete och livet i övrigt) och praktisk. Resultaten i studie II visar fem huvudkategorier med avseende på vad brukare efterfrågar hos sina assistansanordnare; a) en tydlig uppfattning (ideologi) om vad personlig assistans är, b) en god service till brukare, c) en medlande roll mellan brukare och personliga assistenter, d) bra arbetsförhållanden för personliga assistenter, e) ett samhällsengagemang i frågor som berör människor med funktionshinder.

Studie III undersöker hur tillfredsställda brukare är med sina assistansanordnare, samt anordnarnas assistenter. Ett frågeformulär distribuerades till samtliga brukare i Göteborgs kommun med personlig assistans mer än 20 timmar per vecka och som var över 18 år (473 brukare). Brukarnas tillfredsställelse mättes genom tre olika mått. Det första måttet var en fråga till brukaren om hur bra assistansanordnaren uppfattades. Det andra måttet byggde på de fem aspekter som brukare efterfrågade hos sina anordnare, och som framkom under intervjuerna i studie II. Det tredje måttet byggde på de tio aspekterna som brukarna efterfrågade av sina personliga assistenter, och som framkom under intervjuerna i studie I. De två första måtten visar att brukare med alternativa assistansanordnare (privata bolag och brukarkooperativ) är mer nöjda med hur personlig assistans anordnas än brukare med kommunal assistansanordnare. Beträffande det tredje måttet, anordnarnas personliga assistenter, fanns det inga signifikanta skillnader i tillfredsställelse mellan brukare med olika anordnare.

Syftet med studie IV var att undersöka om antalet assistanstimmar skiljer sig åt mellan olika anordnare. En timme assistans kostar lika mycket oavsett vilken anordnare som brukaren har anlitat. Studien visar dock att brukare i Göteborgs kommun med privata bolag som anordnare har tilldelats fler assistanstimmar under perioden 1994-2006 än brukare med kommunal assistansanordnare. Enligt studien har brukare som anordnat sin assistans genom privata bolag, tilldelats drygt 18 procent fler timmar under perioden 1994-2006, jämfört med kommunala brukare. Om en brukare har haft ett privat bolag istället för kommunen under perioden 1994-2006, motsvarar detta en ökad direkt kostnad för staten (via Försäkringskassan) på över två miljoner kronor. Detta resultat kan förklaras utifrån olika vinstintressen mellan privata och offentliga anordnare, eller genom att brukares behov tillvaratas olika hos privata respektive offentliga anordnare.

Assistanslagens intentioner är att främja jämlikhet i levnadsvillkor och full delaktighet i samhällslivet för människor med funktionshinder. Det är därför av särskild betydelse att förstå varför brukare med kommunala assistansanordnare har tilldelats färre assistanstimmar än brukare med privata bolag, samt hur detta är relaterat till den upplevda tillfredsställelsen i stödet personlig assistans.

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John Magnus Roos
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Table of contents

Introduction

> “Certain social groups deserve so-called special considerations and entitlements. They deserve these for the perfectly good democratic reason that, without them, they would be open to abuse and exploitation by more powerful groups and forces (government, markets and corporations, for example) which could not be relied on to protect the rights and interests of others. As an idea and an ideal, then, democracy acknowledges that between the many different interests in a society there are unequal relations of power, and so it acts to give power to those interests which on their own are less equal than others.” (Lucy & Mickler, 2006, p. 2)

The reform of personal assistance

Background of the reform of personal assistance

The perspective on people with disabilities and society’s support for them has varied during the history of the modern welfare state. In the 1950’s, the Swedish ideology of support was based on defining a handicap as an individual attribute, and society’s policy was aimed at physically separating “handicapped people” from other citizens. During the 1960’s both politicians and researchers changed their conceptions of handicaps and disabilities. Instead of referring to handicapped people focus shifted to “people with disabilities”. Within this discourse, disability must be distinguished from the individual. The individual is not to be defined by her/his disability or equated with the disability. In this view the handicap is determined by society; the physical environment, attitudes and the organisation of society’s supporting measures. Focus was shifted from the individual to conditions in society. During the 1970’s the big institutions were closed and integration and normalisation became the new buzzwords. However, it was not enough that those words were written in the political agenda, it was also necessary to implement them in society. According to debaters, people with disabilities lacked participation, integrity and influence even in the late 1980’s (Hugemark & Wahlström, 2002). The institutions for people with disabilities created and confirmed a status of incompetence and dependency for people with disabilities. Institutions have been criticized for viewing a group of persons according to a collective label which legitimate standardised routines instead of a flexible and individual-oriented support (Söder, 1989). Institutions do not only segregate people physically. According to Söder (1989), the institutions also segregated people through social constructions of the meaning of disability, which influenced both the self-image of people with disabilities and their image in mainstream society.

In 1988 a special parliamentary commission, the Disability Commission (DC), was appointed by the Swedish Government to investigate the situation for children, younger persons and adults in Sweden with severe functional impairments. The broad-based composition of the DC included representatives of all the parliamentary political parties, the entire disability movement, the national associations of county councils and municipalities, national authorities and other bodies. Altogether, the DC had 11 members, 14 special advisers and 3 expert advisers (SOU 1991:46).

The goal of the DC was to investigate the living conditions of people with disabilities. Where improvements were needed, the DC was to put forward proposals in order to assure that people with disabilities received effective support in becoming full participants in society (SOU 1991:46).

The DC has conducted interviews and questionnaires with both users and contact persons of the support and service providers available to persons with disabilities. Their findings highlight critical shortcomings concerning full participation, self-determination and equality. The DC concluded that the Health and Medical Care Act (1982:763), the Social Services Act (1980:620) and the Care of the Mentally Retarded Act (1985:568) were not sufficient to guarantee good living conditions, for people with disabilities, and that structural changes were therefore necessary in order to improve the situation for people with disabilities. The DC was especially concerned with the following questions; personal assistance; the necessity of a law on civic rights for the users; and the freedom of choice through a variety of producers of services, but with governmental funding and regulation (SOU 1991:46). The policy reforms were implicit in the criticism: “Institutions should be abolished, integration instead of segregation, more flexible services and less power to professionals.” (Söder, 1989, p. 121).

One important actor in the debate during the 1980’s was the Independent Living Movement (IL). IL is originally an American civil rights movement. One important part of the IL-ideology is the right to self-determination for people with disabilities. They stated that the right to self-determination was particularly important when it comes to support for private and intimate needs (e.g. feeding, personal hygiene and communication). For such support, the IL recommended personal assistance (Gough, 1995). The focus of IL is on barriers which exclude people with disabilities from participating in society. The IL is strongly influenced by a market-based consumer ideology, with its emphasis on consumer autonomy and the freedom to choose (Askheim, 2005). During the 1980's, people with physical disabilities started two IL user-cooperatives in Sweden, STIL in Stockholm and GIL in Gothenburg (Gough, 1995). With economic support from the municipality the users received the responsibility to cover their needs for support by employing their own personal assistants. Some other actors started assistance-projects similar to the IL cooperatives (Askheim, 2005; Hugemark & Whalström, 2002).

In 1991 personal assistance had already emerged as a social service in many municipalities in Sweden. However, this form of personal support was not available everywhere and there were geographical inequalities in the support given to people with equivalent needs. The DC stated that the availability of assistance must be reinforced in order to improve freedom of choice, autonomy and continuity in everyday life. The DC recommended that the Support and Service Act (i.e. LSS) should include entitlement to a personal assistant for everybody deemed to need such a service and included in the population to which LSS refers. The DC recommended that the municipality should have the basic duty of supplying and financing personal assistance, but that the individual personally could act as employer or engage, for instance, a cooperative as an employer. According to the DC, personal assistance should take people with disabilities away from institutions toward full-participation in society (e.g. work, school etc.). The DC also proposed that the financial support for personal assistance must be arranged as a social insurance (SOU 1991:46).

Personal assistance according to Swedish law

The breakthrough for the arrangement of personal assistance in Sweden is dated to 1994, when two particular acts came into force: "Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments" and "The Assistance Benefit Act (1993:389)". These acts entailed that personal assistance was established as an individual right for *users* (see "terminology") who qualified for the service (SOU 2005:100).

> “We believe that legislation is needed as part of the process of asserting the position of the individual in society and giving him/her (and his or her next-of-kin) a means of influencing their situation. But also in order for him/her to be able to take part in the development of society and to fashion the society in which children, young children, young persons and adults with extensive functional impairments are automatically included and respected in the general diversity.” (SOU 1991:46, p. 6)

Personal assistance refers to personally designed support that is provided by a limited number of persons for persons who, owing to major and lasting functional impairments, need assistance with their basic needs. Basic needs are defined as; ”…personal hygiene, meals, dressing and undressing, communication with others or other help that requires extensive knowledge about the person with a functional impairment.” (Act 1993:387, §9a). If a person needs personal assistance for her/his basic needs he/she can also receive personal assistance for other personal needs if those needs are not satisfied in another way. Personal assistance should promote equality in living conditions and full participation in society. The aim of personal assistance is to give users the possibility “to live as others do” (Act 1993: 387, § 5; Act 1993: 389).

Users who receive personal assistance should not live in group housing or be cared for at an institution (Swedish Social Insurance Agency, 2007a). There is no lower age restriction for when personal assistance should be provided, but the user must have been granted assistance before the age of 65, and the number of hours can not be increased after the age of 65 (Act 1993:387; Norström & Thunved, 2008).

The municipality is financially responsible for users who need assistance for less than 20 hours a week. If a person needs personal assistance for their basic needs for more than 20 hours a week, he/she may be entitled to assistance benefits. Besides assistance for basic needs, the assistance benefit should support the user with a wide range of services in areas such as working life, leisure activities, cleaning and other areas (Grönvik, 2007). The right to this benefit is regulated in the “Assistance Benefit Act (1993:389)”. The Swedish Social Insurance Agency takes the decision on assistance benefits. The municipality is financially liable for the first 20 hours in such cases too (Swedish Social Insurance Agency, 2007a).

The “Assistance Benefit Act (1993:389)” contains regulations relating to the distribution of public funds for the cost of personal assistance. The act does not regulate the practical provision of personal assistance. The act is written in order to give the user influence over how the support is provided. The user can decide how the assistance should be arranged, for instance:

- The user can start a business of her-/his own and employ her/his assistants.
- The user can request assistance through the municipality
- The user can form an association or cooperation with other users and employ several assistants.
- The user can consult another company or organisation.
- The user can combine different alternatives above (Swedish Social Insurance Agency, 2007a).

Terminology

The concepts of disability and impairment

Disability is a concept with many meanings. A functional-ability-based perspective focuses on an individual’s *bodily functions*; on a person’s functional abilities and limitations. An environmental (or relative) perspective on disability views a disability as a *relation* (or interaction) between an individual and her/his environment. A social model of disability views disability as *barriers* in society which prevent people with impairments from fully participating in society (Grönvik, 2007).

The present study has an environmental perspective on disability and views disability as an interaction (or relation) between the individual’s impairments and the structure and function of society (Grönvik, 2007). The United Nations have used an environmental perspective on disability since 1981 (Hjelmquist, 2008). According to the Swedish reform of personal assistance, disability refers to a relation between the impairment (e.g. injury or disease) and the person’s environment. Such a perspective is important for two reasons; (1) it stresses that disability is not a property of the individual and (2) it creates possibilities for change (SOU 1991:46).

According to Hydén, Nilholm and Karlsson (2003), there is a risk that environmental and social disability research is too focused on a medical-bodily function of disability. Too often the social model of disability relate the body to medicine and understands impairment in terms of medical discourse, instead of viewing the impaired body as a part of the domain of history, culture and meaning (Hughes & Paterson, 1997). Further, in practical and administrative contexts, it is also difficult to use an environmental perspective on disability. The intention with the legalisation of personal assistance, as previously described, was to include people with disabilities as one more aspect of the diversity of human existence (SOU 1991:46). According to Hjelmquist (2000), it seems as people with disabilities first need to be excluded from the society, through some classification of illness, in order to be included in it. This paradox, illustrates how difficult it is to turn the environmental perspective into practice, and why therefore both academy and practice maintain to view disability through a functional-ability based perspective. The environmental perspective on disability used in the present study considers interactions between users and personal assistants and between users and External assistance providers, EAPs (see "*The concepts of user, personal assistant and External assistance provider").* Such interactions are influenced by the Swedish assistance market and the Swedish government, which in turn are influenced by culture and history (Figure 1).

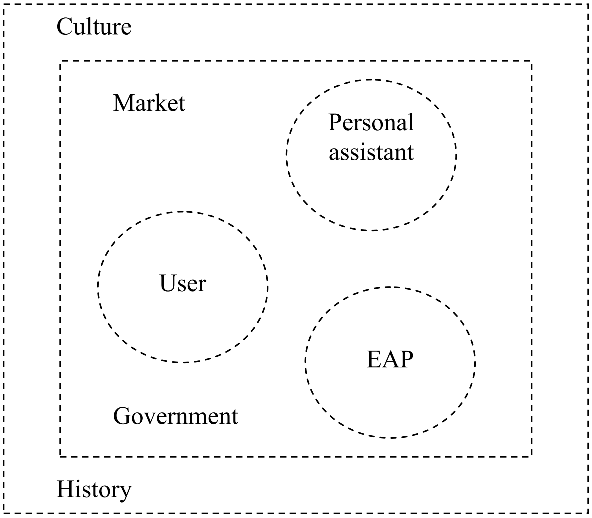

Figure 1. The environmental perspective on disability used in the present thesis.

Note. Disability can be related to all interactions between the user and her/his environment.

The present study views a person with a disability as a person who for one reason or another is put in problematic/difficult situations when he/she enters a physical or social environment that is not accessible (Grönvik, 2007). However, problematic situations sound negative. It is important to clarify that I do not have any normative preconceived opinion of what personal assistance ought to do, such as “overcome handicaps that would otherwise prevent the achieving of a full human experience” (Laswell, 1951, p. 477), or make it “possible for the private individual concerned to live as others do” (Act 1993:387, § 5). I see a risk in such statements; that disability is viewed as a tragedy, caused by an impairment which must be repaired/fixed. It is important to remember that several people with severe disabilities are already satisfied with who they are, and are able to reach their life goals despite, or even because, of their impairments (Albrecht & Devlieger, 1999).

The present thesis has used diagnoses/impairments to classify people with disabilities in different categories. For instance, I have used the “International Classification of Diseases” (ICD). The ICD is a classification of diseases and other health problems, primarily used in epidemiological and clinical contexts and for health management purposes (World Health Organisation, 2008). The Swedish law of personal assistance (Act 1993:387) states that the right to personal assistance should be based on the person’s needs of assistance and not on diagnoses or impairments. According to Hjelmquist (2000), disability can arise without identification of any medical impairment (e.g. panic disorder). Changes in cognitive capacity can also be registered before the onset of a disease (Nuechterlein, Dawson, Gitlin, Ventura, Goldstein et al, 1992). The present study use impairment (e.g. injury or disease) as one factor, among several, that might explain the concept disability. The concept “people with disabilities” is in itself misleading and confusing. Because, the disability does not need to be within the user, it can be caused by something outside the user. I define the concept “people with disabilities” as people *with* a need of special considerations and entitlements. This need can be caused by the impairment and/or something outside the person. (We define need as that which is necessary for an organism’s health and well being; see “*The concepts need and desire”*).

The concepts of user, personal assistant and External assistance provider

A user is a person with a disability who consumes personal assistance. According to Swedish law (Act 1993:389), users qualified for personal assistance comprise three different categories of people:

1. Users with “mental retardation”, with autism or with an autism-like condition (Act 1993:387). Medical diagnoses determine if a person belongs to this category. The diagnosis mental retardation implies an intellectual disability which has arisen before the age of 16 and which is major and causes considerable difficulties in daily life and, consequently, an extensive need for support and service. The diagnosis autism or autism-like condition refers to a major personality disorder which arises during childhood, usually before the age of seven. The disorder affects the person’s social ability, communication and behaviour. Autism and autism-like conditions are usually life-long (Dehlin, 1997).

2. Users with a considerable and permanent intellectual functional impairment after brain injury in adult age (≥16) (Act 1993:387). The impairment must have been caused by external force (e.g. road accidents, falling or maltreatment) or physical illness (e.g. tumours, inflammations and cerebral haemorrhage). People with mental disorders are not included in this category (Dehlin, 1997).

3. Users with some other lasting physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are major and cause considerable difficulties in daily life and, consequently, an extensive need for support and service (Act 1993:387). This category consists of children and adults with long lasting needs of habilitation and rehabilitation. The category includes people with physical disabilities, people with mental disorders and people with intellectual disabilities who have difficulties doing things, due to an injury or disease, in their daily life. People belonging to this category may for example be those with severely impaired vision or hearing, gastrointestinal diseases, and individuals with some kinds of brain injuries leading to reduced abilities to perform certain activities. Neither the medical diagnosis nor the reasons for the disabilities are of crucial importance, what

matters is that the person has major difficulties coping with her or his basic needs by her-/himself (Dehlin, 1997).

The heterogeneous categories of people enumerated above are administrative instruments, used for instance by the Swedish Social Insurance Agency in order to motivate the assistance eligibility for different claimants. The three categories are not motivated by scientific considerations but reflect administrative/judicial ambitions.

A personal assistant is a person who works for a user of personal assistance. According to the law, the term personal assistant implies that the support needed by the user in all situations is provided by a limited number of persons (Act 1993:387). According to the political objectives of the reform, a personal assistant should be attached to the user and not to any particular activity. Also, a user should have personal influence over the support, for instance over who is employed as a personal assistant, and who is not (SOU 1991:46).

The concept External assistance provider (EPA) has not been used in previous research or by any actor on the assistance market. There is no general concept for all external actors who assist/support/help users with personal assistance (A. Barsk Holmbom, personal communication, September 13, 2007; P. Alexandersson, personal communication, October 11, 2007). According to Norén (2000), there are three main types of external actors who provide assistance; municipalities, user-cooperatives and private firms (Figure 2). Different sources (i.e. researchers and organisations) which refer to EAPs use their own concepts, which reflect their perspective on personal assistance. Such concepts are; service provider (Independent Living Institute, 2006); assistance provider (JAG, 2007); organising body (Swedish Social Insurance Agency, 2007a); producers (Norén, 2000); employer of the assistants (Askheim, 2005). External assistance provider is chosen here because it is a broad concept which can include all the different perspectives. It is important that the concept is not given a narrow meaning before I have explored what the concept is about. All EAPs are formal employers of their assistants. According to Swedish law, they are responsible for many aspects of working conditions, ranging from working environment to sick leave. In general they also manage financial administration and recruitment of their personal assistants (Norén, 2000).

The present study's definition of External assistance provider is; the municipality, a user-cooperative or a private firm that is the formal employer of the user's personal assistants and that might also support the user with other tasks related to personal assistance.

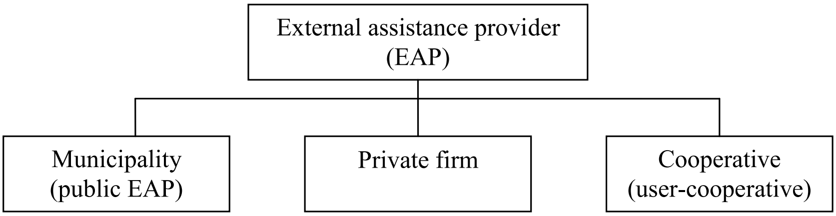

Figure 2. Three types of External assistance providers.

The concepts of need and desire

In the psychology of motivation the concept of need is used as a basis for understanding action (Maslow, 1970). I have no intention of explaining behaviour with Maslow's theory about needs and motivation. I use the theory in order to motivate why I choose the concept desire as a research tool, *instead of the concept need*. According to Maslow (1970), satisfaction of unsatisfied needs is an end-goal of all human actions. Desires are surface indicators of needs and therefore only means to an end, while needs are ends in themselves:

> "Usually when a conscious desire is analyzed we find that we can go behind it, so to speak, to other, more fundamental aims of the individual…It is characteristic of this deeper analysis that it will always lead ultimately to certain goals or needs behind which we cannot go, that is, to certain need satisfactions that seem to be ends in themselves and seem not to need any further justification or demonstration." (Maslow, 1970, p. 5)

Needs are sometimes unconscious which imply that people are not able to directly articulate them. Irvine (2006) distinguished between instrumental desires and terminal desires.

Instrumental desires imply wanting in order to fulfil some other desires. When Maslow (1970) refers to desires it is these instrumental desires he means. According to Irvine (2006), all our desires can not be instrumental: “Suppose I want A, because I want B, which I want because I want C, which I want because I want D, and so on. This chain of desires can be very long, but it must finally end in something I want for its own sake.” (Irvine, 2006, p. 55). Those terminal desires are analogue to what Maslow (1970) refers to as needs.

Maslow (1970) is one of the most well-known persons in psychology but his theories of needs seem to have little empirical support (Sopre, Milford & Rosenthal, 1995; Wahba & Bridwell, 1976). The ambition of the present thesis is not to analyse the users’ desires of personal assistance according to Maslow’s approach, in order to find their underlying needs. Using Maslow’s theory of needs runs the risk of narrowing the focus down to his categories thus forcing a particular interpretation upon the data and possibly missing other more relevant characteristics. Another risk would be that I might come to view needs of assistance as individual attributes, as lacks or deficits within users[1], rather then viewing personal assistance as relations between users, personal assistants and External assistance providers. According to Franken (as cited in Arvidsson, 2004), it is more appropriate to ask people what they want rather than relying on unsupported theories of needs.

The present study defines a desire as what someone wants (Irvine, 2006). What a customer wants is what the customer hopes or wishes to receive from a particular service (Zeithaml, Bitner & Gremler, 2006). The present study does not distinguish between instrumental desires and terminal desires.

I use a very broad definition of needs: “That which is necessary for an organism’s health and well being.” (Harré & Lamb, 1982, p. 409).

The concept of quality

The concept of quality does not have one single definition and it can be defined from several different perspectives. The context in which quality is referred to (e.g. manufacturing,

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[1] In psychology, a need is often defined as “a physical state involving any lack or deficit within the organism” (Atkinson, Atkinson, Smith, Bem and Nolen-Hoeksema, 2000, p. 703).

business and the service marketing industry) often determines the perspective on and the definition of quality (O'Reilly, 2007).

According to Øvretveit (1992), health care quality refers to quality at three different levels: individual-, organisational- and societal level. This implies that high quality health care exists when health care (1) meet the desire of the consumers (i.e. patients or users), (2) is produced at the lowest possible cost to the health care organisation and (3) is produced within a reasonable societal budget (Øvretveit, 1992). According to Calnan (1988), health care should be evaluated both from a patient/user perspective and from a cost perspective. This thesis combines a user perspective and a cost perspective of the concept quality. The present thesis is divided in four different studies. The first three studies view quality from a user perspective while the fourth study views quality from a cost perspective.

The first three studies view quality in a service marketing context where quality is defined as customer satisfaction (Gummesson, 1993; Grönroos, 2007; Vukmir, 2006). Satisfaction is the consumer's fulfilment response. It is a judgment that the product or service provides a pleasurable level of consumption-related fulfilment (Oliver, 1997). According to O'Reilly (2007), there has been considerable debate in the literature regarding how service quality is distinguished from customer satisfaction. Most researchers agree (Cronin & Taylor, 1992; Parasuraman et al., 1994, cited in O'Reilly, 2007) that customer satisfaction is specific to one unique service while service quality is a more general concept. The concepts seem to be synonyms as long as the measurement of service quality is based on attributes relevant for customer evaluation of the particular service, and not on standard surveys (O'Reilly, 2007).

The fourth study is a cost analysis (Drummond et al., 2005) of different EAPs. In this final study the fact that quality in a public health care system is dependent on cost efficiency and spending limitations is taken into consideration. It is a fact that government can not afford to pay for or ensure access to health care without limitations for all its citizens (Eiriz & Figueiredo, 2005). Swedish personal assistance is completely financed by the government which implies that costs of assistance providers are costs of the society.

The present thesis will not investigate quality of personal assistance from the perspective of personal assistants or representatives of EAPs.

The concepts of attribute and attitude

On the basis of direct observation or information received from outside sources or by way of various inference processes, a person associates an object with a number of attributes. In this manner, the person forms beliefs and attitudes about himself, about other people, about institutions, behaviours, events etc. (Fishbein & Ajzen, 1975). The present study defines an attribute as "a quality, character, characteristic, or property attributed as belonging to a person, thing, group, etc." (The New Webster's encyclopedic dictionary of the English language, 1997, p. 43).

A classical definition of attitude is "a mental and neutral state of readiness/…/learned pre-dispositions to respond to an object." (Allport, 1935, p. 810). According to Fishbein and Ajzen (1975), those responses might be either favourable or unfavourable. They view an attitude to a specific object as the sum of the products of two subscales; (1) beliefs about the object being related to relevant attributes and (2) evaluations (e.g. liking or disliking) of each attribute. (Fishbein & Ajzen, 1975). Using this approach, an attitude toward an object can be represented as:

$$A_O = \sum_{i=1}^{n} b_i e_i$$

Where A_O is the attitude toward a specific object; b_i is the belief i about the object, i.e. the subjective probability that the object is related to attribute i; e_i is the evaluation of attribute i; and n is the number of attributes.

Several researchers (e.g. Fishbein & Ajzen, 1975; Triandis, 1971; Kinnear & Taylor, 1996) proposed that the attitude concept consists of three different components:

1) The cognitive component. This component includes awareness and knowledge of the object.
2) The affective component. This component includes liking and preference of the object.
3) The conative component (or the behavioural component). This component includes the intention to act and actions.

An attitude can be related to any one of the three components, and does not need to include all components simultaneously (Eagly & Chaiken, 1993). According to Rossister & Percy (1998), an attitude toward an object is an overall summary of the specific object in the person's mind. The attitude is a result of a cognitive component and an affective component, as well as "freestanding" emotions. The emotions are called freestanding because they are not connected to beliefs. However, they do contribute to the overall attitude. Freestanding emotions operate as unvoiced feelings. Such a freestanding emotion might for example be a feeling of coldness (Rossister & Percy, 1998).

The present study views an attitude toward an object[2] in two different ways:

- Overall summary of the object (in congruence with Rossister & Percy, 1998).
- A sum of belief evaluations of all relevant attributes of the object (in congruence with Fishbein and Ajzen (1975), and as described in the formula above).

Personal assistance in practice

Swedish users of personal assistance

In 2007, the total number of users of personal assistance in Sweden was 18167 persons. Of the total number, 3341 users received assistance according to the "Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments" (i.e. less than 20 assistance hours per week), and 14826 users received assistance according to the "Assistance Benefit Act (1993:389)" (SOU, 2008:77).

Among the 14826 users who received personal assistance according to the "Assistance Benefit Act (1993:389)", 53 percent were men and 47 percent were women. In 2007, the average number of assistance hours per week was higher for men (M = 108) than for women (M = 104). Among users with personal assistance according to the "Assistance Benefit Act (1993:389)", 35 percent belong to category 1; 6 percent belong to category 2 and 57 percent belong to category 3 (category information was not available for 2 percent of the users). Considering users with assistance according to the "Assistance Benefit Act (1993:389)", users

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[2] Anything that becomes an object of thought can serve as an attitude object. Some attitude objects are abstract (e.g. liberalism), and others are concrete (e.g. a chair) (Eagly & Chaiken, 1993).

who belonged to category 2 received more assistance hours on average than users in other categories (SOU 2008:77). The distribution of age across different categories and genders is illustrated in Table 1.

Table 1

Characteristics of users with personal assistance according to the "Assistance Benefit Act (1993:389)", in Sweden in 2007

	Category 1		Category 2		Category 3	
Age	Women	Men	Women	Men	Women	Men
0-19	832	1181	-	-	386	526
20-29	596	785	14	24	267	337
30-39	407	458	24	62	363	436
40-49	236	293	57	96	653	588
50-59	124	144	108	160	1019	883
60-	81	76	127	170	1555	1415

Since the beginning of the reform, the market share of municipal providers has continuously decreased (from 70 percent to 55 percent) in favour of private firms and user-cooperatives. In 2007, the market shares for users with assistance according to the "Assistance Benefit Act (1993:389)" were divided as follows; the municipality 55%, private firms 30% and user-cooperatives 11%. Approximately 3 % of the users did not arrange their personal assistance through EAPs (information is not available for approximately 2 percent of the users) (SOU 2008:77).

Three types of External assistance providers

Different perspectives on personal assistance

According to Norén (2000), different types of External assistance providers have different perspectives on what personal assistance is about. Personal assistance for the municipality is about providing personal assistants who can execute different kind of tasks for the user (Norén, 2000). The provision of personal assistance by the municipality is characterised by top-down decisions and standardized user support (Hugemark & Wahlström, 2002). The provision of personal assistance by a user-cooperative on the other hand, is characterised by user autonomy and self-determination of users (Askheim, 2005). According to Norén (2000), cooperatives and private firms prefer to delegate as many tasks as possible to the users. For instance, decisions on salary and education for personal assistants are centralised for the municipality while such decisions usually are handed over to the specific user in the case of a cooperative or a private firm (Norén 2000).

Different legal frameworks

The municipality has a legal responsibility for users of personal assistance. According to the *Instrument of Government*, "…it shall be incumbent upon the public institutions to secure the right to health … and to promote social care and social security" (Act 1974:152 § 2). This implies that the municipality must provide assistance to users who do not choose assistance provider themselves and to users who are, for one reason or another, omitted by other assistance providers. The representatives of the municipality, as public officials, must also follow Swedish legislation in the public sector; *"...public power shall be exercised under the law"* (Act 1974:152 § 1). Representatives of private firms and cooperatives are freer to run personal assistance in their own interest.

Different objectives

The fundamental objective of public health-care organisations is to achieve the best possible service within a limited budget. All public services will be under the same government budget and the overall objective is to allocate the budget in such a way that it will equalise the marginal health gain for each citizen (Jacobsen & Thorsvik, 2008; Le Grand, 2003). The fundamental objective of a private firm is to maximize, or at least to increase significantly, its market value for owners and for other parties who have an interest in the firm (Pinches, 1995). The fundamental objective of a cooperative is to serve the interest of their members and thereby increase the well-being of the members (Nilsson, 1983). According to Jacobsson (2007), the objective of a user-cooperative is to provide good assistance to the users of the cooperative. One of the main challenges for user-cooperatives is to secure user control for people with intellectual disabilities. The user cooperative JAG has developed a model of what they call "service guarantors" to take care of such tasks (JAG, 2007). The service guarantor is a person who knows the user well and who has the task of ensuring that the user is in control of the arrangement of personal assistance. The service guarantor has the responsibility to teach the assistants how to understand the intentions of the user (Askheim, 2003).

Costs of personal assistance

The costs of personal assistance are divided between local councils (i.e. municipalities) and the Swedish government (i.e. the Swedish Social Insurance Agency). Local councils are financially responsible for all users with less than 20 assistance hours per week and for the first 20 hours (per week) for all users with more than 20 assistance hours per week. In 2007, the total cost (i.e. costs of the local councils and the Swedish government) for users with assistance according to the "Assistance Benefit Act (1993:389)" was 18 billion SEK (SOU 2008:77). Since 1994, this cost has increased by 14.5 billion (i.e. 414 percents) (Figure 3).

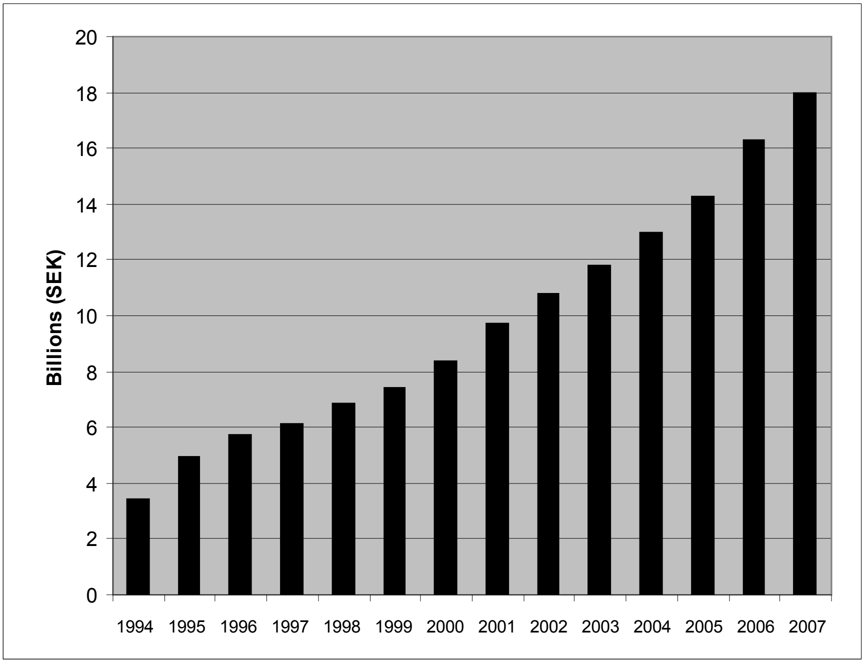

Figure 3. Total costs for personal assistance according to the "Assistance Benefit Act (1993:389)" during the period 1994 – 2007, according to the price level in 2007 (SOU, 2005:100; Swedish Social Insurance Agency, 2007b).

The costs of personal assistance are considerably higher than estimated in the beginning of the reform (Swedish Social Insurance Agency, 2007b; SOU 2008:77). In relation to users with assistance benefits, there are two main reasons for the increased costs of personal assistance. First, the Disability Commission estimated the number of users of personal assistance according to the "Assistance Benefit Act (1993:389)" at 7000 persons. In 2007, almost 15000 people were recipients of personal assistance according to the "Assistance Benefit Act (1993:389)". Second, the average number of hours per user has increased. Before the reform, the DC and the government estimated the average number of assistance hours per user and week to 40 hours and 45 hours, respectively. During the period 1994 – 2007, the average number of hours per user and week has increased from 66 hours to 106 hours (SOU 2008:77).

Rules and regulations in practice

The "law of rights" implies that the decision process, concerning for example entitlement to personal assistance and number of assistance hours, always starts with a formal application from the user, see Figure 4 (Åström, 1998; Barron, Michailakis & Söder, 2000). If the user is unsatisfied with the decision by the Swedish Social Insurance Agency, he/she can appeal to an administrative court (RiR, 2004:7).

Rules and regulations related to personal assistance are unclear and open to subjective interpretations (SOU 2008:77; RiR, 2004:7). Decision- makers at the Swedish Social Insurance Agency consider the concept "need" as vague and impossible to judge on objective criteria (RiR, 2004:7). For instance, the law does not specify what is included in the concept "other personal needs", and the government has proposed that this should be made clear and explicit in order to gain control of the cost of personal assistance (Swedish government bill 1995/96:146). One decision-maker stated that "imagination and experience" are necessary ingredients in the decision process (RiR, 2004:7, p. 37). According to Åström (1998), there is no objective definition of the concept "good living conditions", which implies that the decision-makers always have to make subjective interpretations.

Some EAPs give their users judicial support to formulate applications related to personal assistance, handle relations with authorities and to appeal decisions (SOU 2008:77), as one EAP stated: "If necessary, we appeal to the highest administrative court to maximize the number of assistance hours" (Assistansia, 2003). The legal framework and the decision process are not constructed to stand such pressure from professional lawyers, which partly explains the increased number of assistance hours per user (SOU 2008:77).

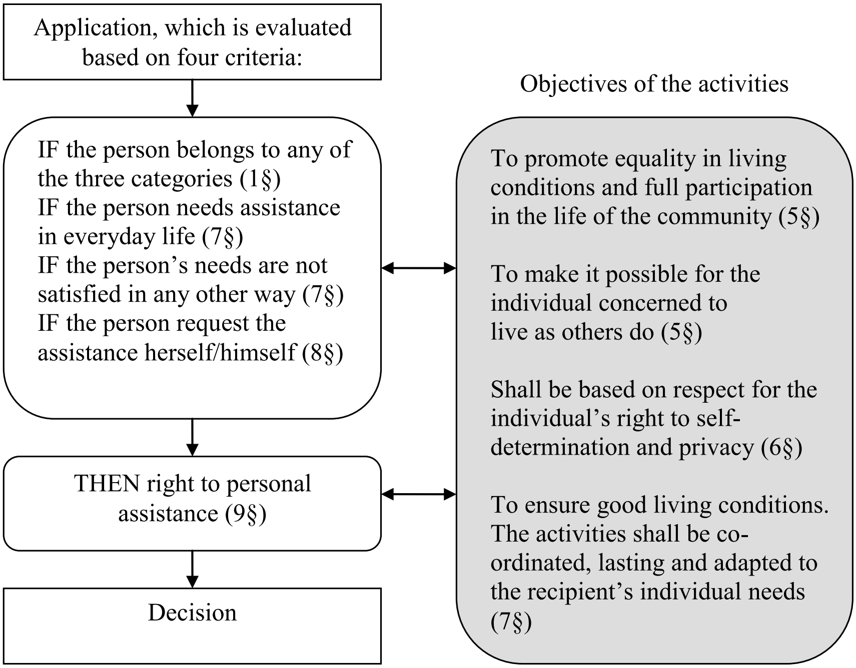

Figure 4. The administrative decision process related to personal assistance (Åström, 1998, p. 100).

Note. The paragraphs are related to the "Act (1993:387) concerning support and service for persons with certain functional impairments". These paragraphs are also used for decisions in the "Assistance Benefit Act (1993:389)".

Summary of the empirical studies

Aims

Research related to people with disabilities often focuses on what experts believe people with disabilities desire. To better design services, researchers must ask people with disabilities what they desire from a specific service. My approach has been to let people with severe disabilities formulate their own perceptions and desires (Gough, 1994; Söder, 1995; Lutz & Bowers, 2005).

Little research has been done regarding what users desire of Swedish personal assistance. When personal assistance was established as a legal right in Sweden, some researchers (e.g. Gough, 1994; Hugemark & Wahlström, 2002) investigated the implications for the users having personal assistance instead of their previous support, i.e. home care. Research has also been conducted in order to follow-up the public intentions of personal assistance (e.g. RiR 2004:7; SOU 2005:100; SOU 2008:77).

Our ambition was to approach the users' desire of personal assistance with an open view. Thus, the first aim of this thesis was of an explorative nature, to explore what people which severe disabilities desire of their personal assistance. The aim has been divided in two research questions:

- What do users of personal assistance desire of their personal assistants? (Study I)
- What do users of personal assistance desire of their External assistance providers? (Study II)

Identification of attributes the user desires of personal assistance is the same as identification of relevant attributes of customer quality (i.e. user satisfaction) of personal assistance. The aim of the first two studies was to identify as many attributes as possible that users desire of personal assistance and thereby lay the foundation for studies of a comparative character. I have strived toward not being influenced by judicial intentions with the reform, or by previous research related to topics that may seem similar to personal assistance (e.g. home care, eldercare, home nursing etc.).

As the market share of private firms has grown continuously since 1994, it is high time that we turn our attention toward understanding more about the different types of EAPs and especially their impact on the consumer service experience. The second aim of this thesis was of a comparative nature, to compare user-satisfaction with personal assistance between different types of External assistance providers. The aim was to investigate if customer satisfaction differs between users who arrange their personal assistance through municipal providers and those using other types of External assistance providers (i.e. private firms and user-cooperatives). The second aim has been formulated in the following research question:

- Does user satisfaction differ between users of different External assistance providers? (Study III)

For an evaluation of different alternatives, it is not enough to compare consequences (e.g. user-satisfaction) of different alternatives. It is also necessary to identify, measure and compare the costs of the alternatives being considered (Drumond et al, 2004). It is true that the societal cost of one assistance hour is the same for all users, but it might be that some EAPs are associated with a higher number of assistance hours than others, and thereby a higher direct cost of personal assistance. Thus, the third aim of this thesis was also of a comparative nature, to compare the number of assistance hours between users who have arranged their personal assistance through the municipality and user who have arranged their personal assistance through a private firm or a user-cooperative, respectively, during the period 1994 – 2006. The starting point was that differences in the EAPs' perspectives of personal assistance, legal frameworks and objectives (as described above), had created different incitements and possibilities to influence the number of assistance hours. The third aim has been formulated in the following research question:

- Does the number of assistance hours differ between users of different External assistance providers?

In the discussion, consequences (Study III) of different EAPs were compared to the costs (Study IV) of different EAPs (Figure 5).

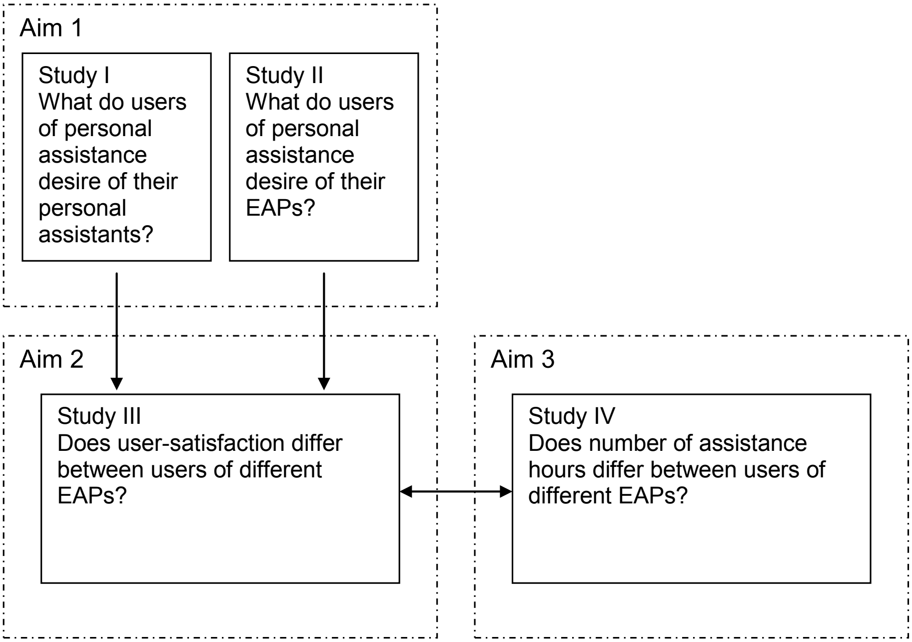

Figure 5. Relation between the aims and the studies.

Participants

Age

The present study has been delimited to users of at least 18 years of age. This delimitation is not related to unique characteristics of users of personal assistance. Rather, I have chosen 18 years of age because this is the age when Swedish citizens legally attain adulthood, which implies that they have reached the status of full judicial citizens. I believe that the inclusion of people younger than 18 years of age would require special research techniques and different ethical considerations. I can, for instance, not assume very young people to be able to speak for themselves.

Assistance according to the "Assistance Benefit Act (1993:389)"

The present study will only consider users who have personal assistance according to the "Assistance Benefit Act 1993:389", in other words users who have personal assistance for basic needs for more than 20 hours a week. This group has been chosen because they are in need of the most comprehensive assistance (Askheim, 2005).

Residents of the area of Gothenburg

The present study only considered users who were residents of the area of Gothenburg (i.e. the municipality of Öckerö[3] and the municipality of Gothenburg). Gothenburg is the second largest city in Sweden, with a population of almost half a million (Municipality of Gothenburg, 2008). Gothenburg was appropriate for comparative studies of EAPs, since all three types of EAPs were well represented in the city (SOU 2005:100). During the period 1994 – 2006, the number of adult users with assistance according to the "Assistance Benefit Act (1993:389)" has increased from 156 persons to 473 persons (Data from local and central registers of the Swedish Social Insurance Agency, collected for Study IV). The increase has been especially large for users with private firms as EAPs (Figure 6). Table 2 (p. 40) describes user characteristics of the 473 users in the municipality of Gothenburg who had personal assistance according to the "Assistance Benefit Act 1993:389" in 2006.

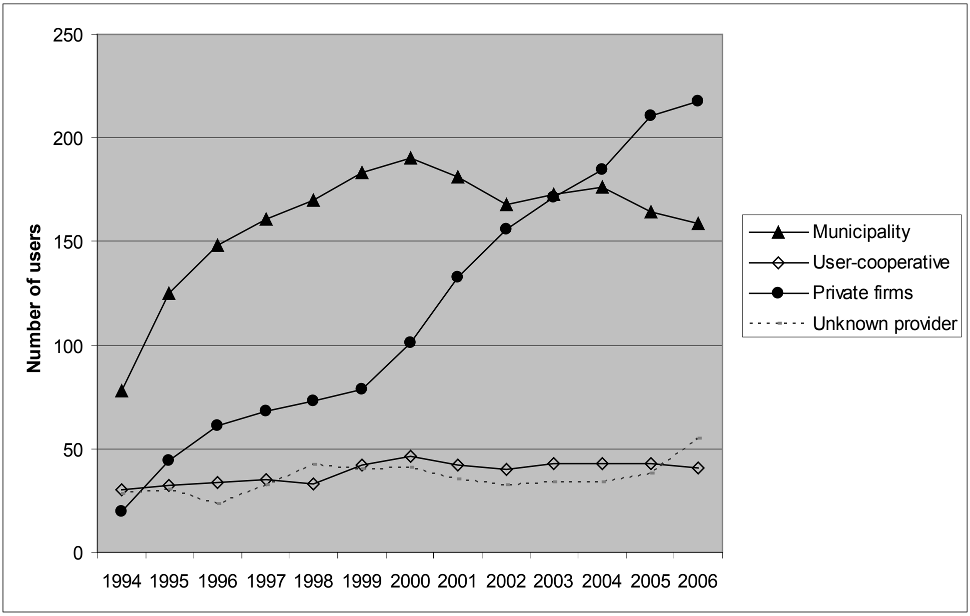

Figure 6. Number of adult users for different EAPs during the period 1994 – 2006, in the municipality of Gothenburg. (Data from central and local registries of the Swedish Social Insurance Agency, November 2006, collected for Study IV.)

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[3] The municipality of Öckerö consists of 10 islands located North West of the municipality of Gothenburg. The population of the municipality of Öckerö is about 12500 persons (Municipality of Öckerö, 2008).

Methods

The qualitative interview (Study I and Study II)

Participants

The sample consisted of 12 users who fulfilled the inclusion criteria, as previously described (see “Participants”). Ten users lived in the municipality of Gothenburg and 2 users lived in the municipality of Öckerö. The gender distribution was 4 men and 8 women. The mean age was 47 (range: from 21 to 65). The mean time for receiving personal assistance was 7 years and 10 months (range: from 1 year and 11 months to 11 years and 9 months) and the average number of assistance hours per week was 118 hours (range: from 40 hours to 224 hours[4]). The EAPs were distributed as follows; 3 users of municipality, 4 users of user-cooperatives and 5 users of private firms. Users qualified for personal assistance comprise three different categories of people (see “The concepts of user, personal assistant and External assistance provider”). Two users belong to category 1, one user belongs to category 2 and nine users belong to category 3. Considering the type of impairment, the participants represent a very heterogeneous group (e.g. people with physical disabilities only, and people with mental and behavioural disorders).

Sample procedure

Users who participated in a related quantitative study (Roos, 2003) were asked to participate in an interview. The original inquiry about participation was mailed to 291 users, who were randomly selected from the total population of 474 users who received assistance according to the “Assistance Benefit Act” in the area of Gothenburg in April 2003 (Roos, 2003). A total of 27 users consented to participation in an interview and among those, 10 users were selected in order to represent the wide spectrum of users as regards impairments, EAP and demographic characters. The 27 users were under-representative of men and users who had a municipal EAP. In October 2006, an invitation was therefore mailed to 20 men with a municipal EAP. Four users consented to an interview and among those two were selected in order to increase the diversity among participants.

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[4] 224 assistant hours per week means that the user has at least two assistants during some hours.

Instrumental design and data collection

The 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 characteristics of a personal assistant?", "What is characteristic of a bad assistant?", "What is characteristic of a good assistant?", "Do you find your personal assistants to be lacking in any way?", "How do you perceive quality concerning personal assistants?" "What are important characteristic features of an EAP?", "What is characteristic of a bad EAP?", "What is characteristic of a good EAP?", "Do you find your EAP lacking in any way?", "How do you perceive quality concerning an EAP?". This type of question invites participation and narration. The questions overlapped and were only brought up if the free conversation did not cover them. The questions were also adapted to the individual's ability to respond (e.g. some respondents prefer to talk in concrete terms of good and bad assistants, while others could relate to more abstract attributes of quality concerning personal assistants more easily). The interview lasted between 45 and 80 minutes. The interviews were tape recorded and transcribed verbatim prior to analysis.

Information about the interview was mailed to the 12 users and they were free to decide the time and place of the interview. Data collection took place between June 13, 2005 and October 27, 2006. Ten interviews were conducted in the homes of the users and two interviews took place at the Department of Psychology, University of Gothenburg. Three users were not able to fully participate in the interview, due to their impairments. In these cases, I involved "significant others". "Significant others" are persons (e.g. parents or social workers) that represent the users (Tøssebro, 1998). The "significant others" were requested to try to only consider the perspective of the user they represent. In two of the three cases, the users were able to participate and the "significant others" (e.g. mother and personal assistant respectively), were asked to act as an interpreter. In one interview participation was not possible and the user was completely represented by her mother.

Data analysis

Content analysis was performed in this study (Krippendorff, 1980; Berg, 2004 and Schilling, 2006). In keeping with the aim of the study, the content was divided into two domains: "desired attributes of personal assistants" and "desired attributes of EAP". The text, in each of the two domains, was first divided into *meaning units*; transcribed verbal expressions whose content corresponded to the aim of each study. 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).

From qualitative attributes to survey questions

In the present study, I have moved from qualitative methods to quantitative methods. According to Kvale (1996), a qualitative analysis is used to identify the attributes of an essence while a quantitative analysis is used to determine the amounts and proportions of those attributes. The present study used qualitative interviews to identify desired attributes of personal assistance and quantitative analyses to determine amounts and proportions of quality attributes of different EAPs, in order to compare user-satisfaction between them (Figure 7).

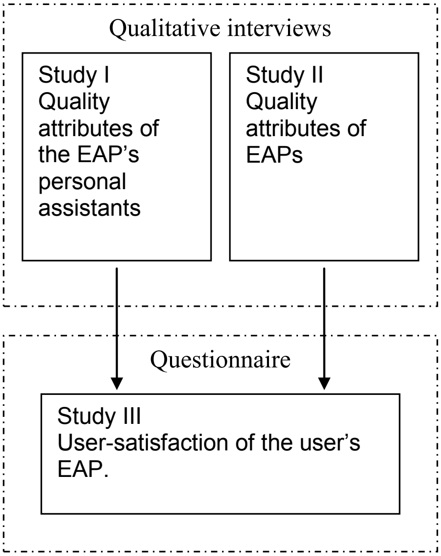

Figure 7. The link between interviews and questionnaire

According to Mishler (1986, p. 26), theories are weak if they are based on ad hoc theoretical explanations after the fact, rather than “real social units of action and meaning” (i.e. participants in an interview context). In order to capture attitudes related to daily life conditions, a questionnaire must be based on the people it concerns (Mishler, 1986). Since there was no extensive literature on what Swedish users of personal assistance desire of personal assistance, I needed to collect such data, inductively.

In the developing process, from interviews to survey questions, I consulted members of a specialist group dealing with persons with long-term illness and functional disabilities at the Vårdal Institute. For feedback on the questionnaire, I consulted members of the “Health, Handicap and Aging research group” at the Department of Psychology, University of Gothenburg. The general opinion was that the questionnaire was good. The critique was that some questions were too abstract, for instance the attributes “discreet” and “obedient” related to quality attributes of personal assistants, and the attributes “proper ideology” and “mediating between user and personal assistants” related to quality attributes of EAP. The attributes were rephrased in order to be more unambiguous, clear and simple. Finally, I conducted a pilot study with the 12 users who participated in the qualitative interviews. In the pilot study, I compared the responses in the questionnaires with the original interview texts. If I found discrepancies in the significances of attributes between the interview texts and the questionnaire responses, or if the users wrote that something was unclear, I consulted them by telephone (n = 3). After the pilot study, I specified the attribute “informative” with examples from real life contexts, such as “inform me if they take the last thing from the fridge or if it is dirty somewhere”. All survey questions about attributes have been derived verbally from the interview texts, and the pilot study verified that the rephrased attributes corresponded to the same content as the original desires from the interviews.

Questionnaire (Study III)

Participants

The mailing list for the questionnaire (i.e. the population frame) was adult users who received assistance according to “The Assistance Benefit Act (1993:389)” in the municipality of Gothenburg in November 2006 (Table 2).

Table 2

Characteristics of adult users with personal assistance according to the "Assistance Benefit Act (1993:389)", in the municipality of Gothenburg in 2006.

	Municipality (n = 159)		Private (n = 218)		Cooperative (n = 41)		Total (N = 473)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Demographics								
Age	46	16	44	15	43	14	44	15
Gender (women)	41%		46%		54%		44%	
Nationality (Non-Swedish)	23%		22%		17%		20%	
Type of impairment Administrative categories (Swedish Social Insurance Agency)								
Category 1	30%		23%		21%		25%	
Category 2	12%		6%		10%		8%	
Category 3	58%		71%		69%		67%	
Type of impairment ICD-10 (World Health Organization)								
Mental and behavioural disorders	33%		26%		29%		28%	
External causes of morbidity	7%		7%		3%		8%	
Diseases of the nervous system	49%		53%		54%		51%	
Diseases of the musculoskeletal system and connective tissue	5%		9%		7%		8%	
Other health problems and unspecified health problems	6%		5%		7%		5%	
Years with personal assistance	7	4	5	3	7	4	6	4
Number of assistance hours per week	97	47	121	50	112	44	111	49

Note. The discrepancies in number of users between the three type of EAPs and total is explained by users with unknown EAP. Users who arrange their personal assistance themselves are included in private. (Data from central and local registries of the Swedish Social Insurance Agency, November 2006).

The *population frame* (Dahmström, 1991) of 473 users was based on users who fulfilled the inclusion criteria in November 2006, while the questionnaire was distributed in August 2008. A total of 33 envelopes were returned as the addressees were unknown. This implied that at least 33 users who fulfilled the inclusion criteria in November 2006, for one reason or another, did not fulfil the inclusion criteria in August 2008. Further, this also meant that the present study excludes people who have received personal assistance later than November 2006. Therefore, the actual reach of the survey was 440 users.

The population-frame included users who arranged their personal assistance themselves. I do not know how many users in the municipality of Gothenburg who arrange their personal assistance themselves instead of using an EAP. The proportion of Swedish users who do not have an EAP is approximately 3 percent (SOU 2008:77). I assume that the proportion in Gothenburg is the same as in the rest of Sweden, which gives me an estimated population of 427 users.

A total of 179 users answered the questionnaire. I excluded questionnaires from 11 users who arranged their personal assistance themselves. The estimated response rate was 39.3 percent (168 users of 427). Table 3 summarise user characteristics of the participants.

Data collection

On the 11th of August 2008, the questionnaire was sent out, together with a stamped addressed envelope and a cover letter explaining the study. To increase the response rate, a reminder was sent out on the 27th of August. Both letters also included information to the users' administrator, in cases when the users were not able to give consent to participation themselves. Instead of omitting users with severe disabilities, I asked "significant" others (e.g. parents and social workers) to answer the questionnaire (Tøssebro, 1998).

Table 3

Characteristics of participants in Study III

	M		*SD*
Demographics			
Age	48.2		14.9
Gender (women)		47.0%	
Nationality (Non-Swedish)		10.3%	
Type of impairment			
Administrative categories (Swedish Social Insurance Agency)			
Category 1		23.0%	
Category 2		27.3%	
Category 3		49.7%	
Physical only		63.3%	
Years with personal assistance	10.0		4.0
Number of assistance hours per week	115.9		53.6
Type of EAP			
Municipality		35.1%	
Private firm		55.4%	
User-cooperative		9.5%	

Instrumental design

The questionnaire covered areas such as age, gender, nationality (i.e. "Swedish" or "Other than Swedish"), hours per week of personal assistance, number of years using personal assistance, number of years with current EAP, type of impairment (e.g. physical disability and/or mental disability/intellectual disability), relations to personal assistants at the time of employing them (i.e. familiar assistants, such as family member or friend, or non-familiar assistant), and attitudes to EAP and personal assistants. The questionnaire also included a question about user involvement in the study (in order to measure whether the answers reflected the user's own perceptions or if the user has been influenced/represented by a "significant" other). In this study, attitude measurements are used to determine customer-satisfaction (Kinnear & Taylor, 1996). To increase reliability, I used three different variables to measure user-satisfaction of EAPs:

(1) Direct attitude to the EAP. The question read: “How good is your EAP?” The response format was a 5-point Likert scale, ranging from very bad to very good (Katona & Likert, 1946).

(2) A *multiattribute attitude model* (Fishbein & Ajzen, 1975) based on attributes related to the EAP. This variable is the sum of the products of the two subscales, beliefs about the EAP and belief evaluation (Fishbein & Ajzen, 1975). The attributes were derived from qualitative interviews (Study II). For each attribute, the question read: “Indicate how well you think the statement is applicable to your EAP”. ”I think my EAP (attribute)”. A 7-point Likert scale was used, ranging from “completely disagree” to “completely agree”. The belief evaluation items referred to the importance of each attribute, and were measured on a 7-point bipolar Likert scale, varying from “extremely unimportant” to “extremely important”. In Likert scaling, disagreement with an item is assumed to be indicative of the person’s attitude. Thus disagreement with a negative statement is taken as an indication of a positive attitude (Fishbein & Ajzen, 1975).

(3) A multiattribute attitude model based on the EAP’s personal assistants. This variable is the sum of the products of the two subscales, beliefs about the EAPs’ personal assistants and belief evaluation (Fishbein & Ajzen, 1975). The specific attributes were generated from qualitative interviews (Study I). The item read: “I think my personal assistants are (attribute)?” and were measured on a 7-point Likert scale, varying from “completely disagree” to “completely agree”. The belief evaluation items asked about the importance of each attribute, and were measured on a 7-point bipolar Likert scale, ranging from “extremely unimportant” to “extremely important” (Fishbein & Ajzen, 1975).

Data analysis

Mann-Whitney tests were used as the assumption of normally-distributed data was violated and since logarithmic transformations did not correct the problem. The test variables were (1) direct attitude to EAPs, (2) sum of relevant attributes of the EAP, and (3) sum of relevant attributes of the EAPs’ personal assistants. The grouping variable in each of the three Mann-Whitney tests was type of EAP; i.e. municipal EAP or other type of EAP (i.e. a private firm or user-cooperative).

In the first analysis, I used the complete case approach for dealing with missing data and only included observations with complete data on both test variable and grouping variable (Hair, Anderson, Tatham & Black, 1998). The test variables in the second and third analyses consist of several products of relevant attributes. In these analyses, an observation was included if data were completed for at least 80 percent of the products. All statistical analyses were performed using the SPSS statistical software package.

Government data sources (Study IV)

Participants

The study includes all adult users in the municipality of Gothenburg, who have received personal assistance according to "The Assistance Benefit Act 1993:389" for at least one year (November data) from the 15th of November 1994 until the 15th of November 2006. The study includes 4564 observations of 657 users of personal assistance. Characteristics of the users in the study are described in Table 4.

Instrumental design and data collection

The present study used a longitudinal research design. All data were derived retrospectively from central and local registries at the Swedish Social Insurance Agency.

The dependent variable was number of assistance hours per week on the 15th of November every year. Independent variables have been gender, nationality (i.e. "Swedish" or "Other than Swedish"), age, years with personal assistance, type of impairment, and type of EAP. Type of impairment has been measured through:

(1) Type of impairment as defined by the Swedish Act (1993:387); category 1, category 2 and category 3, as previously described.

Table 4

Characteristics of participants in Study IV

Demographics	
Gender (women)	44.1%
Nationality (Non-Swedish)	18.4%
Type of impairment	
Administrative categories (Swedish Social Insurance Agency)	
Category 1	22.4%
Category 2	8.1%
Category 3	69.5%
ICD-10 (World Health Organisation)	
Mental and behavioural disorders	27.4%
External causes of morbidity	7.5%
Diseases of the nervous system	51.9%
Diseases of the musculoskeletal system and connective tissue	7.0%
Other health problems	2.1%
Unspecified health problems	4.1%

Note. Appendix A gives a more detailed description of ICD-10.

(2) The tenth revision of the International Statistical Classification of Diseases and Related Health Problems, ICD-10, (World Health Organisation, 2008). The population has been divided into six categories:

Category 1:	People with all kind of mental and behavioural disorders, whatever reason for the disorder (e.g. inborn, disease, birth trauma or external cause).
Category 2:	People with disabilities caused by external forces. The category excludes people who acquire a mental or behavioural disorder as a consequence of the external causes. The category also excludes birth trauma and obstetric trauma.

Category 3: People with diseases of the nervous system. The category excludes people with diseases caused by external forces and people who also have mental and behavioural disorders besides the diseases.

Category 4: People with diseases of the musculoskeletal system and connective tissues. The category excludes people with diseases caused by external forces and people who also have mental and behavioural disorders besides the diseases.

Category 5: People whose health problems belong to other categories of the ICD-10 than the four described above.

Category 6: People with unspecified health problems.

There reasons for using ICD-10 in this study were twofold. First, people with mental impairments may have less possibility to influence their own number of assistance hours, than people with only physical disabilities. People in category 1 always have an intellectual disability, while people in category 3 and 4 sometimes only have a physical disability. Further, I think that people in category 3 more often have mental impairments than people in category 4. Second, people with health problems caused by external factors (i.e. category 2) may differ in their motivation to apply for more assistance hours than people with health problems caused by biological factors.

The Swedish Social Insurance Agency does not categorise people according to the ICD-10. However, information from documents at the Swedish Social Insurance Agency (e.g. decisions on assistance benefits, medicine notes etc.), corresponded to the ICD-10 diagnoses. The categories were conducted through a bottom-up process, from individual diagnoses and health problems. The six categories are mutually exclusive and the categorising procedure is described in Appendix B.

Data analysis

Panel data regression methods were used as the assumption of independence between observations was violated; hence I had longitudinal data on the number of hours granted per week each year for each user. The dependent variable was number of assistance hours per week. This variable was skewed to the left (Figure 8) and therefore a logarithmic transformation was used in the panel data regression (Figure 9).

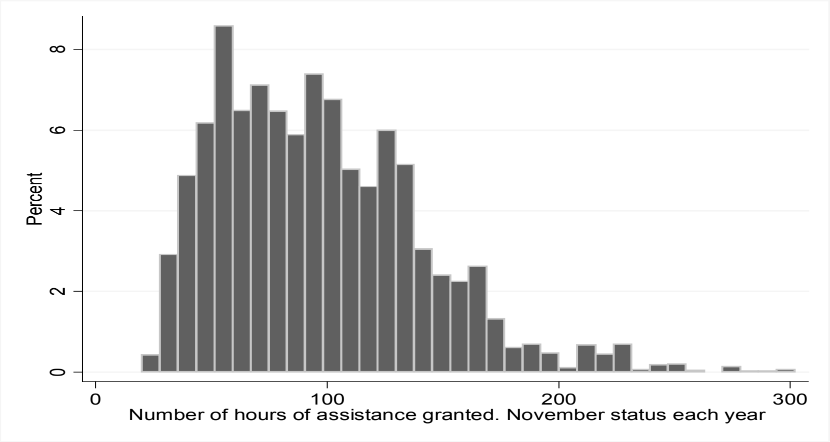

Figure 8. Histogram of number of hours per week distributed over percentage of users. (Data from central and local registries of the Swedish Social Insurance Agency, November each year.)

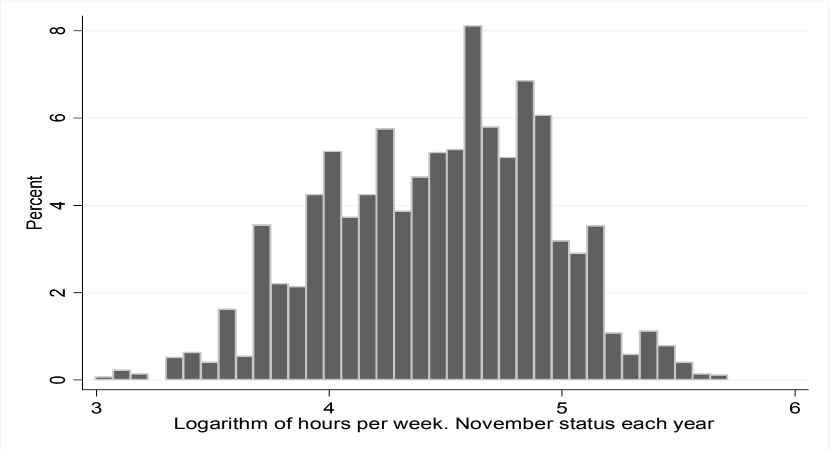

Figure 9. Histogram of logarithm of number of hours per week distributed over percentage of users. (Data from central and local registries of the Swedish Social Insurance Agency, November each year.)

The analyses controlled for the effects of gender, age, nationality, type of impairment and years using personal assistance. For most users (n = 599) I also had more than one observation, which allowed me to control for individual specific variance across time. I present the estimated equations by random effects for the standard model (Jones, 2007; StataCorp, 2007). The random effects models treat the individual-specific effects as randomly distributed across individuals and parameters are estimated for time-varying and time invariant variables. Coefficients from logarithmic models are interpreted as percentage effect of an independent variable upon a dependent variable. The present study considered a p-value of 0.05 as statistically significant. All statistical analyses were performed using Stata v10.0 (StataCorp, 2007).

Ethical considerations

According to The Freedom of the Press Act (1949:105), the right of access to official documents may be restricted if it is necessary to protect the personal circumstances of private subjects. In order to protect the privacy of the users, the information about them is not available to anyone except authorized persons.

For the interviews, nine users were able to give informed consent to participate in the study themselves. In three cases, the users gave informed consents through legal guardians. Before the user consented to participate, all contacts between the researchers and the user were meditated by the Swedish Social Insurance Agency in Gothenburg.

The questionnaires were distributed by the Swedish Social Insurance Agency and the research team did not have access to the mailing list. Before the user (or the administrator) consented to participate (by answering the questionnaire), all contact between the researchers and the users was mediated by the Swedish Social Insurance Agency in Gothenburg. The study is in accordance with the Swedish law on research ethics and approved by the regional ethical review board in Gothenburg (GO 082-08).

All data from the government was collected by administrative employees at the Swedish Social Insurance Agency in Gothenburg (i.e. local data) and Sundsvall (i.e. central data). All subjects were connected to the data through an anonymized link. The research team only received the link and thereby no personal identify information. The study was approved by the regional ethical review board in Lund (dnr 563/2006).

Results

What do users of personal assistance desire of their personal assistants? (Study I)

The analysis of the interviews, concerning desired attributes of personal assistants, resulted in a taxonomy of 10 attributes of how the users would like their assistants to be:

- Discreet; the assistant should keep a low profile. The discreet attribute of an assistant can be related to the user; the assistant should, for instance, be able to handle emotional reactions from the user without becoming personally involved. The discreet attribute can also be related to a third person, e.g. staying in the background when the user meets family and friends.
- Obedient; the assistant should act as the user tells him/her to. The obedient attribute can be related to a task the user would like the assistant to perform, for instance to clean a window. The obedient attribute can also be related to a specific process the user would like to feel control over, for instance cooking a dinner according to the user's preferences.
- Reliable; the assistant should be someone the user can trust. A reliable assistant adheres to client confidentiality laws and time schedules. Being a reliable assistant also includes that the user believes that the assistant will execute tasks efficiently and carefully.
- Informative; the assistant should be able to communicate useful information. An informative assistant is able to communicate what is happening in the world, for instance when he/she washes the user's body or takes the last things from the fridge. The user should also communicate with other assistants in order to carry out routine tasks in the same way.
- Alert; the assistant should provide help or take action if it becomes necessary. An alert assistant should sometimes take the initiative and step in when the user needs assistance in a specific situation, for instance cutting onions when making meatballs. An alert assistant sometimes just waits for the user's initiative and must then change very quickly from being passive to being very active, for instance assisting the user with personal hygiene (going to the bathroom) during a work meeting.
- Respectful; the assistant should respect the user as an equal human being. The user desires the assistants to be able "to look beyond the handicap" and respect the user for the person the user is.

- Considerate; the assistant should care about the user. A considerate assistant pays attention to the user's needs, wishes and feelings and is kind to the user. Characteristics of a considerate assistant are that he/she focuses on the user, makes efforts to understand the user, encourages the user and feels a sense of responsibility for the user.
- Friendly; the assistant should be kind and act toward the user like a friend. A friendly assistant is someone the user can talk personally to and together with whom the user can do things.
- Pleased; the assistant should be satisfied with the user, the work and life in general.
- Practical; the assistant should successfully deal with concrete tasks in the user's real life (e.g. support the user with personal hygiene and dressing, vacuum cleaning, cooking etc.).

What do users of personal assistance desire of their EAPs? (Study II)

The analysis of the interviews, concerning desired attributes of EAPs, revealed 19 attributes. Those 19 attributes were possible to cluster into five broader groups of categories (Figure 10).

a. Having a proper ideology of personal assistance. A proper ideology is built on three attributes; (1) following the legal framework of personal assistance, (2) having the user's well-being as first priority and (3) adapting the assistance to the specific user's need of assistance.
b. Interacting with the user in a service-minded way. Nine attributes describe this category; (4) empowering the user, (5) caring about the user, (6) supporting the user when the user asks for a favour, (7) reducing the user's workload related to personal assistants, (8) providing assistants in all situations, (9) providing a limited number of assistants to the specific user, (10) arranging training for users/legal guardians, (11) arranging social activities for users, (12) covering extra costs related to personal assistants.
c. Mediating between users and personal assistants. Two attributes - (13) arranging meetings and (14) handling conflicts between the user and the assistant – are used to describe this category. The users want personal meetings as preventive measures to keep up a good

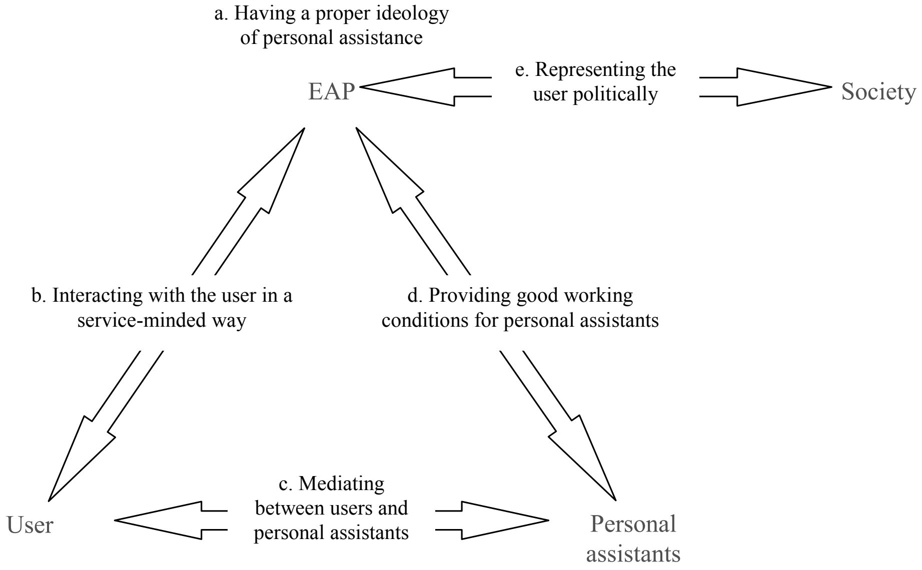

Figure 10. Matrix of actors and five categories of desired attributes of the EAP from the perspective of the user.

relationship between themselves and their assistants, while they would prefer that the EAP handles conflicts if and when the relationship with the assistant is not satisfactory for one reason or another.

d. Providing good working conditions for personal assistants. Four attributes describe what the users would like the EAP to do for their personal assistants; (15) arrange training, (16) provide good administrative conditions of employment, (17) arrange supervision and (18) provide instrumental rules and instructions for personal assistants.
e. Representing the user politically. This category is built on one attribute – (19) being politically engaged on the behalf of the user. The EAP should defend the institution of personal assistance at a political level, prevent economical reductions related to personal assistance and inform the users what is happening with personal assistance at the political level.

Does user satisfaction differ between users of different EAPs? (Study III)

Two of the three variables for measuring user-satisfaction of EAPs indicated that users who have private EAP (i.e. private firms or user-cooperatives) were significantly ($p < .05$) more satisfied with their EAP than users who have the municipality as EAP:

- To the direct question about user-satisfaction (variable 1), users with private EAP (N = 103, *Mdn* = 4.0, *average rank* = 85.0) reported that they were more satisfied than users with public service providers (N = 55, *Mdn* = 4.0, *average rank* = 69.2), U = 2265, $p < .05$.
- On attitudes to EAP measured through the multi-attribute model of attributes from Study II (variable 2), users with private EAP (N = 107, *Mdn* = 33.5, *average rank* = 87.9) reported that they were more satisfied than users with the municipality as EAP (N = 56, *Mdn* = 28.5, *average rank* = 70.8), U = 2370, $p < 0.05$.
- On attitudes to the EAPs' personal assistants, measured through the multi-attribute model of attitudes from Study I, there were no significant differences between users with private EAP (N = 108, *Mdn* = 50.0, *average rank* = *79.0*) and users with the municipality as EAP (N = 56, *Mdn* = 59.5, *average rank* = 89.25), U = 2646, *ns*.

Does number of assistance hours differ between users of different EAPs? (Study IV)

The median values and mean values in assistance hours between the three different service providers are illustrated in figures 11 and 12 respectively. (Median values are more accurate measure of assistance hours, since the variable "number of assistance hours" was not normal-distributed).

According to Figure 11 and Figure 12, users who have had the municipality as their service provider have received less assistance hours during the period 1994 – 2006, compared to users who have arranged their personal assistance through private firms or user-cooperatives.

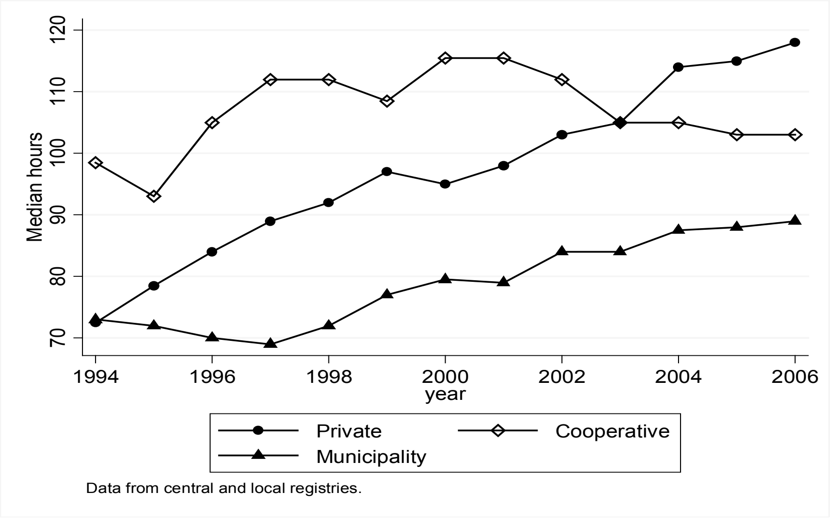

Figure 11. Median values of number of assistance hours by EAP and year. (Data from central and local registries of the Swedish Social Insurance Agency, November each year.)

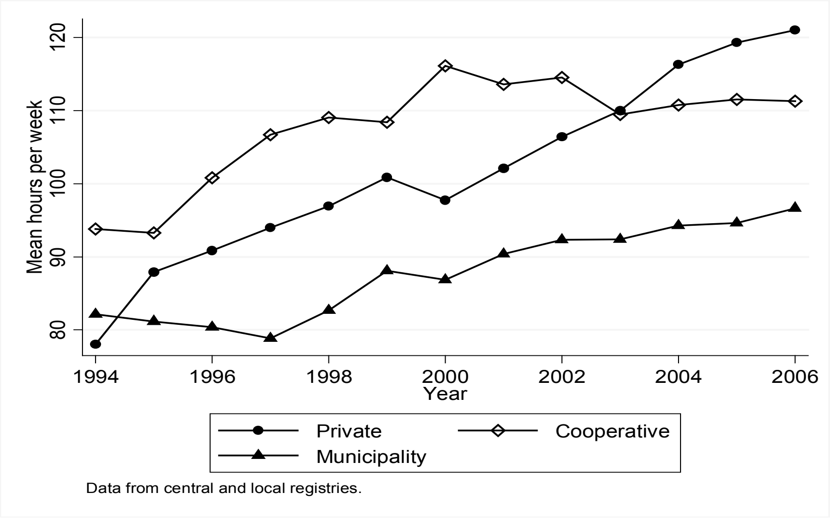

Figure 12. Mean values of number of assistance hours by service provider and year. (Data from central and local registries of the Swedish Social Insurance Agency, November each year.)

During the period 1994 – 2006, an average user with a private service provider received 18.4 percent more assistance hours compared to a user with a municipal EAP, above and beyond the effect of demographic factors (i.e. age, gender and nationality), type of impairment (according to Swedish Social Insurance Agency and ICD-10), years with personal assistance and other individual-specific variation which the panel-data allowed me to control for.

During the period 1994-2006, there was no significant effect ($p<.05$) on the number of assistance hours between an average user with a user-cooperative as EAP and an average user with the municipality as EAP, when I controlled for the effects from demographic factors, type of impairment, years using personal assistance and other individual-specific variation. (The p-value was 0.09.)

Discussion

Quality attributes

Users of personal assistance are sometimes regarded as customers on a service market (Norén, 2000; Hugemark & Wahlström, 2002; Hugemark & Mannerfelt, 2003). Customers do not buy goods or services, they buy the benefits goods and services provide for them (Grönroos, 2007). According to Laswell (1951), the benefits of positive aid are "to overcome handicaps that would otherwise prevent the achieving of a full human experience" (Laswell, 1951, p. 477). However, several people with severe disabilities are satisfied with who they are and are able to reach their life goals despite or even because of their disabilities, despite society's tendency to view disability as a continuing tragedy (Albrecht & Devlieger, 1999). Therefore, I simply asked 12 adult people with severe disabilities what they would like to fulfil with personal assistance (i.e. personal assistants and EAP), instead of relying on some normative idea about "overcome handicaps" or "live as others do" ("Assistance Benefit Act 1993:389").

We found 10 desired attributes of personal assistants and 5 categories of desired attributes of EAPs. It is, however, worth pointing out, that the desire of one user may be contradictory to those of another. For example, some users would like their personal assistants to be their "best friends" while some users think it is important that they do not have a personal relation to their assistants. Some users would like supervision to be available to the personal assistants, while other users are sceptical of the idea of requiring supervision in any form.

The desired attributes of one user may also vary between different situations. An assistant must balance between situations when the user desires closeness and situations when the user would like to distance her-/himself from the assistant. In some situations the assistant should be friendly while the assistant in other situations should almost disappear and become invisible (e.g. discreet). In some social situations, the user desires that the assistant shows the third person that the user belongs to the same party, but in other social situations the user would not like to feel the presence of the assistant at all.

The ability to balance between different attributes is also obvious when it comes to empowerment. Empowering the user is a complex attribute, which must be adapted to the user's unique need for empowerment. The users' desire for self-determination and control may be related to receiving information in a respectful and timely manner when personal assistants and the EAP's representative execute different kinds of tasks for the user. It may also be related to the users being allowed to handle tasks themselves independently without improper meddling from assistants or EAP's representatives. The dilemma is how much personal assistants and EAPs should "take over" instead of respecting the users' right to self-determination. Some users would like their EAP to provide instrumental rules and instructions for personal assistants, while other users view it as a threat against their own right of self-determination. If personal assistants and EAP's representatives take decisions for the user, they must act with respect and care for the user and not take control of the user's life. According to Rivas (2004), users would like to feel that they have accomplished their daily activities by themselves. The present thesis shows that those activities can be almost everything, for instance making meatballs, meeting friends or recruiting personal assistants. The role of the assistance is to empower the user to reach her/his full human potential.

Users are often aware of the fact that it is difficult for one individual personal assistant to satisfy all the desired attributes, and solve this by employing multiple assistants with different attributes who complement each other.

Our ambition with this thesis was to approach the users' desire of personal assistance with an open mind. The aim was not to follow-up the political or judicial motives of the assistance reform. However, it may be interesting to discuss the users' desire for personal assistance in relation to political and judicial intentions. The buzz words were full participation, integration, self-determination and equality (SOU 1991:46; Act 1993:387). The present study points out that the users' desire self-determination and to be respected as equals by their assistants and EAP's representatives. Such desires correspond to political and judicial ambitions. However, the users desire much more from their personal assistance. The present study highlights the desire for a number of social attributes of personal assistants, which can not be found in the law. Users who receive personal assistance are not allowed to live in group housing or institutions (Swedish Social Insurance Agency, 2007a). It is possible that the political goals of full participation have caused isolation rather than participation for some users, and that personal assistance therefore must compensate for a deficit in the users' social needs. One user states:

> "I would very much like to live at a care centre. Even if it meant that I lost the progress I have made, even if I were to be treated like a small child and have to put up with the staff talking about me over my head, I want to get out of here. It's what I really want. I can't face the idea of living here next year – not for a single day. It's about loneliness, very much about loneliness."

According to Goffman (1961), a person who chooses to live at an institute trades her/his freedom for security. Considering Maslow's theory of needs, it is necessary to develop both security and social relations to be able to reach self-actualization (Maslow, 1970). For some people with disabilities, it might be hard to live in society. The present study shows what kind of attributes people with severe disabilities desire of personal assistance in order to reach full participation and integration in society, and thereby to reach their full human potential.

According to Söder (1989), institutions for people with disabilities have created a negative label of the concept disability – a homogenous and segregated group of people. To avoid a negative labelling effect it is necessary to attach an alternative meaning to the concept of disability (Söder, 1989). The huge spectrum of desired attributes and the variation between different users' conceptions of desired attributes related to personal assistance shows that people with disabilities are a very heterogeneous group of people. The huge variation of desired attributes of assistants and EAPs also shows how completely wrong the institutions were when they treated people with standardised routines. It is worth noting that some users do not desire that their EAPs provide activities for their users, because they do not view disability as a reason for companionship.

Flexible and individually oriented support, can however also be criticized. The law is very unclear considering for what kind of needs the user may receive assistance. If there are no clear judicial instructions for what should be included in personal assistance, there must be a risk that some users receive more assistance than others, due to other factors than the actual need of assistance (e.g. some are better at describing what needs they would like the assistance to fulfil). In order to provide equality between different users and in order to control the costs of the assistance reform, it is necessary to define what needs users can expect to satisfy using personal assistance (Swedish government bill, 1995/96:1461995).

From qualitative research to quantitative research

There is an increased interest in combining quantitative and qualitative research methods (Hammersley, 1999; Arksey & Knight, 1999). Qualitative research differs from quantitative research in some methodological aspects. Qualitative research assumes that the external world does not exist outside our knowledge, just interpretations of it, and therefore, qualitative research rejects every possibility of representing reality (Hammersley, 1999). The origin of surveys lies in two intellectual inclinations; the first to generalise, and the second to ask questions (Mishler, 1986). In my case, the quality attributes which were derived from the interviews (Study I and Study II) must be representative for all users in the municipality of Gothenburg, otherwise the questionnaire (Study III) was not a valid instrument. According to Mishler (1986), the wish to generalise can be implemented by sampling procedures (Mishler, 1986). For the qualitative interviews, I selected users in order to represent the wide spectrum of users, as regards impairment, EAP and demographic characters. With a few caveats, it is reasonable that the interview sample is representative of the population; users in the municipality of Gothenburg (Table 5).

According to Table 5, the participants in the qualitative study are, however, over-represented by women. It is possible that men desire other attributes than women and that the questionnaire is based foremost on what women desire of their personal assistants. Further, the qualitative studies are also over-representative of users with user-cooperatives as EAPs. The quantitative analysis compared users with the municipality as EAP with users with other EAPs (i.e. private firms and user-cooperatives). The qualitative study would have been more representative if it had included more users with a municipal provider.

An interview is a face-to-face verbal interchange, shaped by a psychological and a sociological context, while a survey entails asking questions without any verbal interchange (Mishler, 1986). In order to construct a valid instrument, which corresponded to the rich and deep interviews, I involved users of personal assistance and researchers from the University of Gothenburg and the Vårdal Institute, in the operationalisation process.

An extended discussion of quantitative and qualitative methods is beyond the scope and intent of this thesis. Here, it must suffice to note that the generalisation and the way of asking questions in a survey, is always open to criticism. I would like to argue that a strength of the present survey study, is that the quality concept is based on attributes relevant for customer evaluation of the particular service.

Table 5

Relations between participants in the qualitative study and the population

	Interview	Population
Demographics		
Age (M)	47	44
Gender (women %)	67	44
Nationality (other than Swedish %)	8	20
Type of impairment		
Administrative categories		
(Swedish Social Insurance Agency)		
Category 1	17	25
Category 2	8	8
Category 3	75	67
Type of External assistance provider		
Municipality	25	38
Private firm	42	52
User-cooperative	33	10
Years with personal assistance	8	6
Number of assistance hours per week	118	111

Customer-satisfaction of different EAPs

The present study found differences in customer-satisfaction among users with different EAPs. Users of personal assistance are more satisfied with other EAP (i.e. user-cooperatives and private firms) than the municipality. Unfortunately, the statistical test (i.e Mann-Whitney test) did not allow me to control for effects from other relevant variables, for instance impairment. Some private firms only provide assistance to people with physical impairments, while the municipality must provide assistance to all users according to the law (SOU, 2005:100).

Critics of voucher systems (such as Swedish personal assistance) point out the risk of "cream-skimming" and deleterious effects on poorer and less attractive customers. In 1991, the Disability Commission considered the risk of segregation; that is to say that municipal assistance providers need to take care of more demanding users, while other providers may "cream skim" the market on more "valuable" or profitable users (SOU 1991:46). Considering Table 2, the municipality has a marginally higher proportion of users with mental and behavioural disorders, compared to private firms and user-cooperatives. When answering the questionnaire in the present study, users with a municipal EAP were represented or influenced by "significant" others significantly ($p<.05$) more often, which might indicate that users with a public EAP are people with more severe impairments than users with other EAPs. In order to explore the effect of impairment(s), and a potential methodological bias of being influenced by a significant other, I carried out separate Mann-Whitney tests (Study III). None of the variables "impairment" and "being influenced by significant other" explained differences in user-satisfaction with EAPs. Therefore, I conclude that impairment is not significantly associated with user-satisfaction with EAPs. Furthermore, people with mental and behavioural disorders (i.e. people with an intellectual disability) are well-represented in the survey[5]. Therefore, it is reasonable to conclude that the segregation the DC was worried about has not been very extensive. Such segregation would, anyhow, not explain differences in perceived customer quality.

The present study indicates that user-satisfaction with personal assistants does not depend on type of EAP. According to Ruth & Benjamin (2008), user-satisfaction with personal assistants

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[5] It is reasonable that the 37 percent of participants who stated that they have other impairments than physical ones (i.e. mental or intellectual) correspond to the proportion of the population. From Study IV, we know that 28 percent of the population has mental and behavioural disorders. We think that some users in other ICD-categories also classify themselves as mentally and/or intellectually impaired.

depends on the relation to personal assistants at the time of employing them. Users who arrange their personal assistants through family members and friends are more satisfied than users who arrange their personal assistants through other, non-familiar persons (Ruth & Benjamin, 2008). A Mann-Whitney test was carried out to investigate if there was a significant difference in user-satisfaction with personal assistants between employing friends or family members and employing others. The test confirmed previous research and states that Swedish users are also more satisfied with their personal assistants when they employ friends and family members than when they employ non-familiar persons.

Despite some differences between the participants and the population, I think that the study is representative of users in the municipality of Gothenburg (Table 6). I would like to discuss four main differences between participants and the population: Firstly, participants in the study are over-represented by people belonging to administrative category 2 (Table 6). There is a risk that users do not know their administrative category, and that the self-estimated impairment does not correspond to the category used by the Swedish Social Insurance Agency (in the questionnaire, both the category number and a description of the category were given, for instance “Administrative category 2: brain damage caused by external force or disease in adult age”). On the other hand, almost all participants answered the question, which is some indication that the participants knew about their administrative category. Secondly, participants had a higher number of assistance hours per week than average users in the municipality of Gothenburg. This might be explained by the over-representation of users with administrative category 2. Users in category 2 receive more assistance hours compared to other users (see “Swedish users of personal assistance”). Thirdly, participants have had personal assistance during a longer period of time than average users in the municipality of Gothenburg. The difference might partly be explained by the lag, from constructing the population frame (i.e. November, 2006) to distributing the questionnaire (i.e. August 2008). The lag implies that all participants in the survey have had personal assistance for at least 1 year and 8 months. Fourth, participants were under-representative of people with other nationalities than Swedish. This is probably explained by the fact that the questionnaire was only constructed in Swedish.

Table 6

Relations between participants in the survey study and the population

	Participants	Population
Demographics		
Age (M)	48	44
Gender (women %)	47	44
Nationality (other than Swedish %)	10	20
Type of impairment		
Administrative categories (Swedish Social Insurance Agency)		
Category 1	23	25
Category 2	27	8
Category 3	50	67
Intellectual disability	37	>28
Type of External assistance provider		
Municipality	35	38
Private firm	55	52
User-cooperative	10	10
Years with personal assistance	10	6
Number of assistance hours per week	116	111

Costs of different EAPs

The present study indicates that number of assistance hours for users of personal assistance is influenced by type of EAP. During the period 1994 – 2006, users who arranged their personal assistance through private firms received 18.4 percent more assistance hours per year compared to users who arranged their assistance through the municipality. This was the effect of having a private firm, compared to the municipality as EAP, above and beyond the effects of individual-specific variance that I controlled for. An estimation of the direct costs[6] for the government (i.e. the Swedish Social Insurance Agency) indicate that a user who arranged her/his assistance through a private firm, during the period 1994-2006, has costed 2 065 284 SEK more than a user who arranged her/his assistance through the municipality. This effect is above and beyond the effects of impairments, gender, age, nationality and other individual-specific variance that I have controlled for (Appendix C). Such findings are reasonable for a number of reasons:

- The fundamental objective of a private firm is to maximize the profits for owners and other interests. Income can increase through new customers or *higher* consumption among current customers (Pinches, 1995).
- During the period 1994 – 2006, the Swedish Social Insurance Agency has distributed about 119 billion SEK for users with personal assistance according to "The Assistance Benefit Act (1993:389)" (SOU 2008:77).
- There have not been any barriers to enter the market of Swedish personal assistance (Norén, 2000).
- There are no clear specifications of what should be included in personal assistance (RiR, 2004:7).
- The judicial decision process concerning number of assistance hours has been subjective (RiR, 2004:7; Åström, 1998).
- Private firms have promoted themselves as providers of judicial expertise and used arguments, such as "…if necessary we appeal to the highest administrative court to maximize the number of assistance hours" (Assistansia, 2003).
- There are no clear specifications of what assistance money should be used for (SOU 2005:100; Swedish government bill 1995/96:146; RiR, 2004:7).
- There are no efficient controls over what the assistance money is used for (SOU 2005:100; RiR, 2004:7).

The present study did not find that users with user-cooperatives have systematically received more assistance hours than users with the municipality as EAP. According to Figures 11 and 12, a user with a user-cooperative as EAP received more hours compared to an average user

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[6] The costs the government has paid to the EAPs (on behalf of the users). We do not know how direct costs have influenced other costs related to support for people with disabilities. We do not know how the costs have influenced revenues of users. We do not know the alternative costs of personal assistance.

with the municipality as EAP, but the panel data analysis shows that the observed differences are explained by individual-specific variance and not by the type of EAP. The fundamental objective of a user-cooperative is to provide good assistance to their members rather than to maximize their profits. A member of a user-cooperative might have different roles (for instance owner and user), which sometimes are in conflict (Jacobsson, 2007). It could be that user-cooperatives view personal assistance in a long-term perspective, which will influence their incitements to increase the number of assistance hours. During an interview, I asked the user with a user-cooperative as EAP what she considers as the most important aspect of her EAP:

> ”That you understand what personal assistance is. You have to take it very serious. It is a reform, which can be gone tomorrow. I do not think it will be. But I have no guarantee; I have no guarantees in my life. I plan my every day life, as if the reform would stay. But, you never know. It can…, it can also be gone tomorrow, technically, politically, you never know.”

It is worth noting that the average number of assistance hours per user is higher in the municipality of Gothenburg, than in the rest of Sweden. The proportion of private firms is also considerably higher in the municipality of Gothenburg than in the rest of Sweden. Therefore, it is reasonable that the fast expansion of private firms in Gothenburg during the period 1994 – 2006 (Figure 6), explains why an average user in the municipality of Gothenburg has received more assistance hours compared to an average user of Swedish personal assistance.

Costs versus consequences of different EAPs

The general rule when assessing different alternatives is that the difference in costs is compared with the difference in consequences (Drumond et al., 2004). The present study has found that users who have arranged their personal assistance through private firms have cost (in direct costs) the society more than users who have arranged their personal assistance through the municipality. On the other hand, users who arranged their personal assistance through private firms were, in August 2008, more satisfied with their EAP than users who arranged their personal assistance through the municipality (Figure 13). It is possible that users are more satisfied with their EAP, if the EAP can increase the number of hours of personal assistance. Unfortunately, an incremental analysis of costs on consequences is not possible. I can not analyse the marginal effect of user-satisfaction by increases in number of assistance hours, hence the present study measured costs during the period 1994 – 2006, while it measured consequences in 2008.

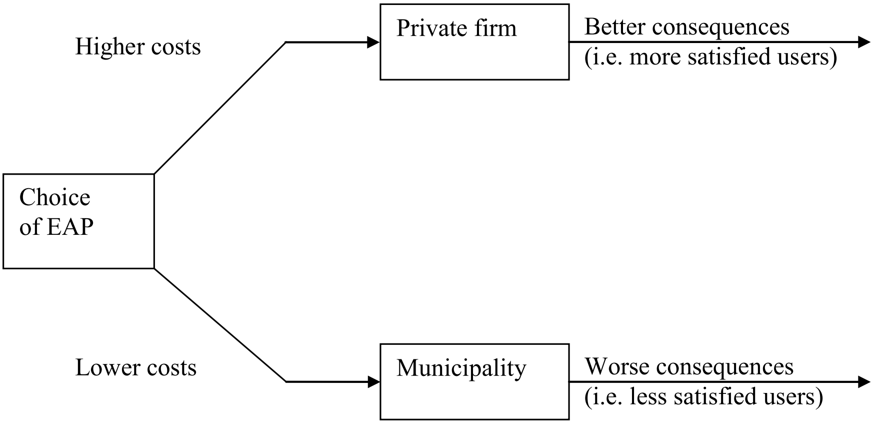

Figure 13. Cost and consequences of private firms and municipality providers.

Another limitation is that I do not know the amount of assistance hours which correspond to the users' actual needs of assistance. Previously, I have explained the increased number of assistance hours through profit-maximization by private firms. However, more satisfied users indicate that a higher number of hours might be motivated according to the users' needs of personal assistance. More satisfied users of private firms than of municipal providers (Study III), give an alternative explanation to the higher number of assistance hours for users with private firms compared to users with municipal providers. The higher number of assistance hours can be explained by the users' needs of personal assistance, instead of profit-maximization. According to such an alternative explanation, the municipality deliver to few hours while private firms better correspond to the real needs of the users.

As previously described, personal assistance is a "law of rights". There is a risk related to the construction of a "law of rights"; the individual her/himself is completely responsible to apply for aid and support. The authorities will not act before they receive a formal application. This implies that the individual must be efficient and take actions her/himself. However, some people with disabilities have difficulties taking initiatives and requiring things of the society they live in (Åström, 1998). According to Lewin (1998), people with disabilities are not always as strong as politicians have assumed. The assumption is that users will demand assistance from society. By contrast, they have been unable to safeguard their interests and to get their needs tested in accordance with the law. This problem is formulated in the paradox; "there is a requirement for more paternalism in order to improve the autonomy of the individual" (Lewin, 1998, p. 222). People with disabilities experience that administrative officers and decision-makers oppose them in all their needs, and that they therefore have to squabble about and appeal every request. They also complain that representatives of the authorities are too busy to respond to their requests and lack the knowledge necessary for providing professional support.

According to the interviews (Study II), some users would like their External assistance providers to assist them in conflicts with the Swedish Social Insurance Agency over the number of assistance hours received. The ambition with personal assistance, according to the law, is to make it possible for people with disabilities to "live as others do". According to the law, a person is entitled personal assistance for needs such as "communicating with others" and "help that requires extensive knowledge about the person". The increased number of assistance hours for users with private firms, compared to users with the municipality, might be motivated according to the law for a number of reasons. Firstly, I do not think that "other" people (i.e. an average person) have to squabble with authorities to the same degree as people with personal assistance. If a representative of the EAP supports the user in contacts with relevant authorities, the user will live more "as others do". Secondly, it is a requirement of personal assistance that it should support users in their communication with others. If a user, for one reason or another, needs assistance in communicating with authorities, this need shall therefore be fulfilled. Thirdly, users experience that executive officers and decision-markers lack the time and knowledge to understand their needs of assistance. A representative of an EAP, on the other hand, might have "extensive knowledge about the person". Therefore, the representative of the EAP might explain the user's needs and living conditions to authorities.

The critical question is therefore; "which EAP corresponds best to the users' actual needs of personal assistance?"

This question is not answered by this thesis. We do, however, need an answer in the future, for ethical, political and economical reasons. An answer is also needed from a legal perspective, as the act of personal assistance has clear objectives concerning welfare and equal distribution. It is clear from the act that distribution of welfare shall be related to the user’s actual need(s) of assistance. The fundamental aim of the law is to promote the welfare of the user and to support her/his independent life, in the name of a democratic perspective on equality (Åström, 1998).

Epilogue

For a long period of time, disability research has been criticised for understanding social contexts through the impaired body (Hugher & Paterson, 1997; Söder, 1995; Hydén, Nilholm & Karlsson, 2003). I think that the medicine-impairment perspective is a rest of the negative labelling effect (Söder, 1989) from a time with institutions. So far, such a perspective has also dominated the society's ideas and provisions of "democratic" support in a time of deinstitutionalisation: "Positive aid is made available in order to overcome handicaps that would otherwise prevent the achieving of a full human experience" (Laswell, 1951, p. 477); "Personal assistance shall make it possible for the individual concerned to live as others do" (Act 1993:387, § 5.)

It is possible that some users need personal assistance to achieve a "full human experience", or in order to "live as others do". However, we have to remember that some people with severe disabilities are able to reach their life goals themselves (Albrecht & Devlieger, 1999). I think that the normative statements above are too simple to describe what disability support is about. I think perspectives such as "achieving a full human experience" and "live as others do" prevent researchers from deeper insights and politicians from efficient governing. The follow-up questions I would like to add are "What do users need to reach their full human potential or to live as others do?" and "Why do users need personal assistance to reach their full human potential or to live as others do?"

The first question is related to the previous discussion about needs and desires (see "terminology"). A "full human experience" or "to live as others do", must be what Irvine (2006) refers to as end goals. Such goals are difficult to make explicit, hence they are deep and sometimes unconscious for users. The reform of personal assistance has been criticised for not defining what should be included in personal assistance (RiR, 2004:7; Swedish government bill 1995/96:146). In the present thesis, I give some more concrete attributes to what users' desires of personal assistance (Study I; Study II). The end goals might be "to live as others do" or to "achieving a full human experience", but such end goals does not give us any operative instruments for providing a high quality service. To achieve good quality, which is client centred and outcome centred, it is essential to adopt a culture of transparency for clients, staff, service-providers and decision-makers (Gupta, 2001). I would like to start this process from the users' desire of personal assistance (Study I; Study II).

The second question, “Why do users need personal assistance to reach their full human potential or to live as others do?”, has already been answered, in the beginning of this thesis: “without them, they would be open to abuse and exploitation by more powerful groups and forces” (Lucy & Mickler, 2006, p. 2). According to such a perspective, the disability is not a property of the individual and it creates possibilities to change (exactly as the Disability Commission proposed, SOU 1991:46). Considering the findings in Study III, a user can change to another EAP than the municipality, and thereby be more satisfied with her/his personal assistance. With such a perspective, the disability still remains inside the user, because it is her/his choice to change. It is very easy to attribute problems to the user, instead of questioning the ”majority” society. I think it is too complex for researchers, politicians, decision makers, administrative staff etc. to distinguish between the users inner and outer worlds. For instance, how much of the impairment and desires, respectively, belong to the users inner world and how much belong to the users outer world (see Figure 1). Therefore, researcher, too often start their environmental analyses from classifications of illness or health problems (for critics, see for example Hjelmquist, 2000). The first three studies of the present thesis have also used the individual as starting point for understanding the user’s environment, but the focus has been the user’s desires of attitude objects, i.e. personal assistants and EAPs, outside the user’s body, instead of the user’s bodily-function. In Study IV, the interaction between the individual and the society is primarily based on incitements by EAPs. According to Study III, type of EAP was associated with user-satisfaction of EAP and according to Study IV, type of EAP was associated with number of hours using personal assistance.

According to an environmental perspective of disability, disability is an interaction between the individual’s impairment(s) and the structure and functions of the society. In the present thesis, I give empirical evidence to such a perspective on disability. I indicate that different organisations, in this case different EAPs, which are shaped by governments and markets (and thereby by history and culture) can be used to explain the concept disability.

> “According to this idea the democratic project remains, and must always remain, unfinished, since there could never come a time when we could be satisfied that we had *enough* democracy, enough freedom, equality and friendship for all the different

social differences there are today and others that may come in the future. In other words, there is no end to the work of democracy.” (Lucy & Mickler, 2006, p. 2)

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Appendix A

Participants in study IV categorised according to the ICD-10

Table 1

Participants in study IV categorised according to the ICD-10 (International Statistical Classification of Diseases and Health Problems)

Category	Frequency (N = 657)
1. Mental and Behavioural disorders	**180**
Mental retardation	134
Organic, including symptomatic, mental disorder	16
Disorders of psychological development	7
Schizophrenia, schizotypal and delusional disorder	6
Mood [affective] disorders	7
Neurotic, stress-related and somatoform disorders	5
Other and unspecified mental and behavioural disorders	5
2. External causes of morbidity	**49**
Transport accidents	21
Other and unspecified external causes of accidental injury	10
Other external causes of morbidity	5
Other and unspecified external causes of morbidity	13
3. Diseases of the nervous system	**341**
Systemic atrophies primarily affecting the central nervous system	37
Demyelinating diseases of the central nervous system	83
Episodic and paroxysmal disorders	11
Diseases of myoneural junction and muscle	22
Cerebral palsy and paralytic syndromes	119
Other and unspecified diseases of the nervous system	69
4. Diseases of the musculoskeletal system and conncective tissue	**46**
Arthropathies	13
Dorsopathies	8
Soft tissue disorders	14
Osteopathies and chondropathies	5
Other and unspecified diseases of the musculoskeletal system and conncective tissue	6
5. Other specified health problem	**14**
6. Unspecified health problem	**27**

Appendix B

Model of the categorising procedure of users according to ICD-10.

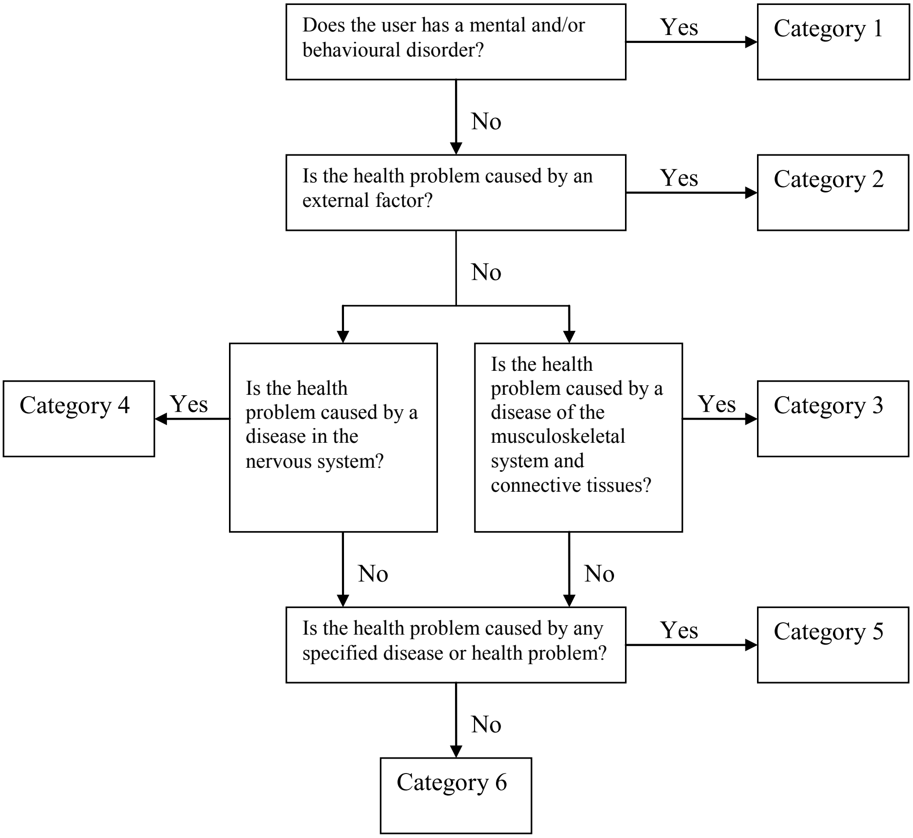

Figure 1. Model of the categorising procedure of users according to ICD-10 (International Statistical Classification of Diseases and Health Problems).

Appendix C

Transformation of percentages of assistance hours to direct costs

Assumptions

- The analysis assumes that the voucher for one assistance hours is constant, 190 SEK during the period 1994 – 2006. [1]
- The analysis excludes users with user-cooperative as EAP and users with unknown EAP. Those groups have been excluded in market shares (*MS*) and in average number of assistance hours per week (*M*).
- The analysis assumes the research period 1994 – 2006 as one unit and does therefore not take into account, for instance, that market shares of private firms and the municipality has varied during the period.

Symbols

MS_M = Market share for the municipality as EAP

MS_P = Market share for private firms as EAP

X_1 = Number of assistance hours per week for an average user with the municipality as EAP

X_2 = Number of assistance hours per week for an average user with a private firms as EAP

M = Average number of assistance hours per week

Formula

$$MS_M(X_1) + MS_P(X_2) = M$$

$X_1 = 1.184X_2$ (18.4 % more hours for private users)

$$MS_M(1.184X_2) + MS_P(X_2) = M$$

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[1] In reality the voucher has varied from 168 SEK – 212 SEK during the period (R. Jönsson, Personal communication, 7th November 2005; SOU 2005:100).

Calculation

$0.61(1.184X_2) + 0.39(X_2) = 97.2$ (97.2 = the average number of hours/week)

$X_2 = 87.39$

$X_1 = 103.47$

$X_1 - X_2 = 16.08$ (16.08 = more hours per week for private user)

$190 * 16.08 = 3055$ (3055 = extra costs per week for a private user)

$3055 * 52 = 158868$ (158868 = extra costs per year for a private user)

$158868 * 13 = 2\ 065\ 284$ (extra costs during the research period for a private user)

Appendix D

The empirical studies

I. Roos, J. M., Hjelmquist, E., & Thorén-Jönsson, A-L. (2009). *What do people with disabilities desire from their personal assistants?* Unpublished manuscript.

II. Roos, J. M., Thorén-Jönsson, A-L., & Hjelmquist, E. (2009). *What do people with disabilities desire from their service organisations of personal assistance?* Unpublished manuscript.

III. Roos, J. M., & Hjelmquist, E. (2009). *Arranging home-based personal assistance through private or public service providers: How satisfied are consumers?* Unpublished manuscript.

IV. Roos, J. M., Hjelmquist, E., & Steen-Carlsson, K. (2009). *Swedish personal assistance; provided according to needs or according to service provider?* Unpublished manuscript.

Running head: QUALITY ATTRIBUTES OF PERSONAL ASSISTANTS

What do people with disabilities desire from their personal assistants?

John Magnus Roos, Erland Hjelmquist and Anna-Lisa Thóren-Jönsson

University of Gothenburg

Correspondence:

John Magnus Roos
Department of Psychology
University of Gothenburg
Box 500
SE – 40530 Göteborg.
Phone: (voice) +46 31 786 1641, (fax) +46 31 786 4628
E-mail: magnus.roos@psy.gu.se

Abstract

This paper aims to explore what people with severe disabilities desire of their personal assistants. Qualitative interviews with 12 adult users of Swedish personal assistance were conducted. The participants represent a very heterogeneous group of people with disabilities, for instance people with diseases of the nervous system, people with diseases of the musculoskeletal system and people with mental and behavioural disorders. The analysis of the interviews revealed in 10 categories of attributes the users desire of their personal assistants: discreet; obedient; reliable; informative; ready; respectful; considerate; friendly; pleased and practical. The importance of attributes seems to vary between different users and between different situations for the same user.

Health and social care services for people with disabilities is increasingly shifting from institutional settings to the private setting of the person's home (Allen & Ciambrone, 2003). Institutions have been criticized for viewing a group of persons according to a collective labelling which legitimates standardised routines instead of a flexible and individual-oriented support (Söder, 1989). A personal assistant is a prototype of a caregiver in the private setting. Personal assistants possess a lower level of formal training than more traditional caregivers, rather they are trained on the job by the caretaker to meet needs that are specific to the individual (Allen & Ciambrone, 2003). However, such a flexible and individually oriented support as personal assistance can also be criticised. The Swedish law for instance, is very unclear considering for what kind of needs the user may receive assistance: "Anyone who needs personal assistance for her or his basic needs is also entitled to measure for other personal needs if these are not satisfied in another way." (Act 1993:387, § 9a). In order to provide equality between different users and in order to control the costs of personal assistance it is necessary to define what users can expect from their personal assistants (Swedish government bill, 1995/96: 146 1995).

Personal assistance implies boundary-crossings between formal and informal roles for both caregivers and caretakers (Allen & Ciambrone, 2003). To the best of our knowledge, no one has investigated what people with disabilities desire from this kind of care delivery in the private setting of the person's home. Research and services related to people with disabilities often focus on what experts believe people with disabilities desire. To better design services, researchers must ask people with disabilities what they desire from a specific service (Gough, 1994;

Söder, 1995; Lutz & Bowers, 2005). To listening to the users is important in purpose to formulate clear judicial instructions for what should be included in personal assistance. Knowledge about what users desire from their assistants can also protect especially vulnerable people, not least people with cognitive disabilities from abuse and exploitation, due to lack of knowledge among personal assistants.

Personal assistance is not only a typical phenomena related to Sweden, it also exists in Norway, Denmark, UK, Germany, Holland, Ireland, US and Australia. Swedish personal assistance is more generous, in respect to governmental funding of assistance (per user), than personal assistance services in other countries (Askheim, 1999, 2005). As a comparison, the American expenditures related to personal assistance have been and still are mainly financed by insurances or personal capital (e.g. the user's salary or financial support from the user's family). The American Public Medicaid Programme has very limited resources and is seen as the last option for people who have no rights to other arrangements. In the UK personal assistance has mainly been financed by the government since 1988, first through trust funds and later through the Health and Social Act. However, the support has been less generous in the beginning of the 21st century and people with disabilities increasingly depend on unpaid "carers" such as friends and family members (Askheim, 2005).

Hugemark and Wahlström (cited in Askheim, 2003) describe three social work ideals which exist in welfare organisations and which also influence the way the assistants perform their work in Sweden; the rehabilitation ideal, the care ideal and the service ideal. The rehabilitation ideal views the user as an object who should be changed or improved by an expert. The expert's action is legitimated through formal merits and professional standards. The care ideal is partly established as a criticism against the rehabilitation ideal. An assistant who works in congruence with the care ideal will view the user as a subject, with unique needs of assistance. This means that the assistant must interact emotionally with the user before her/his actions can be seen as rational. Through dialogue and cooperation the assistant and user will find the best solutions. The care ideal implies that the assistant sometimes takes initiatives her-/himself because the assistant think he/she knows what is best for the user. The service ideal puts the user's self-determination in focus. The user is seen as the expert on her/his own life who knows best what he/she needs. The assistant is seen as an ordinary employee who should execute the "orders" of the user.

Little research has been done regarding what Swedish users desire of their personal assistants. In 1994, when Swedish personal assistance was established as a legal right, some researchers (e.g. Gough, 1994; Hugemark & Wahlström, 2002) investigated the implications for the users with personal assistance instead of the previous support, home care. Users experienced an increased influence and power over the support they received from society, when they shifted from home care to personal assistance (Gough, 1994; Hugemark & Wahlström, 2002). For example, users of home care felt that their support was centrally organized and designed, while users of personal assistance felt that they were free to choose how the support should be arranged; through a private firm, a user-cooperative, the municipality or the user him/herself. Research has also been conducted in order to evaluate the public goals (e.g. judicial and economic) of personal assistance, and to discuss the level of different goal-fulfilments (e.g. National Board of Health and Welfare, 2005; RiR 2004:7; SOU 2005:100, SOU 2008:77).

Swedish personal assistance

According to the Swedish law (Act 1993:387), a personal assistant gives personally designed support to someone who needs personal assistance in order to be able to live as others do. Users qualified for personal assistance are persons who, as a result of severe impairments, have great difficulty in their everyday living and, accordingly, an extensive need of support. According to the Act (1993:387), users qualified for personal assistance comprise three different categories of people:

1. Users with mental impairments, with autism or with an autism-like condition.
2. Users with a considerable and permanent intellectual functional impairment after brain injury in adult age. This only applies to impairment(s) caused by external force or physical illness.
3. Users with some other lasting physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are major and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.

The breakthrough for the arrangement of personal assistance in Sweden came in 1994, when two particular acts came into force: “Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments” and “The

Assistance Benefit Act (1993:389)". Those acts implied that personal assistance was established as an individual right for users who qualified for the service (SOU 2005:100).

The present study will only consider users who have personal assistance according to the "Assistance Benefit Act (1993:389)". To gain access to this support, the user must (a) have been granted assistance before the age of 65, (b) belong to one of the three categories described above, and (c) have a need for basic assistance with tasks such as personal hygiene, eating, dressing and communication that amounts to more than 20 hours a week (Swedish Social Insurance Agency, 2007). If these criteria are fulfilled, the person may receive personal assistance with a wide range of tasks in areas such as working life, leisure activities, cleaning and many other areas (Grönvik, 2007).

Purpose of the study

The aim of this study was to investigate what adult users of Swedish personal assistance desire of their personal assistants. Our ambition was to approach the users' desire of personal assistants with an open view, as unprejudiced as possible. Previous research has had a more comparative approach, relating personal assistance to either the conditions before 1994, general care-giving, or to public goals of personal assistance (Gough,1994; Hugemark & Wahlström, 2002; National Board of Health and Welfare, 2005; RiR 2004:7; SOU 2005:100).

Method

Participants and Recruitment

The sample consisted of 12 users between 21 and 65 years of age with personal assistance according to the "Assistance Benefit Act (1993:387)" (4 men and 8 women, with a mean age of 47 years). The mean duration for having had personal assistance was 7 years and 10 months (ranging from 1 year and 11 months to 11 years and 9 months). The mean time of personal assistance per week was 118 hours, ranging from 40 hours to 224 hours (224 assistant hours per week means that the user had at least two assistants during some hours). Users qualified for Swedish personal assistance comprise three different categories of people, as described previously. In the present study, two users belong to category 1, one user belongs to category 2 and nine users belong to category 3. The participants represent a very heterogeneous group of people with disabilities, for instance people with diseases of the nervous system, people with diseases of the musculoskeletal system and people with mental and behavioural disorders.

In an earlier quantitative study (Roos, 2003), users were asked to answer a questionnaire. In the questionnaire they were asked whether they would be willing to participate in a later interview. The questionnaire was mailed to 291 users, who were randomly selected from the total population of 474 users who received assistance according to the Assistance Benefit Act in the area of Göteborg in April 2003 (Roos, 2003). The response rate of the questionnaire was 72 users. A total of 27 users consented to an interview and among them where 10 interview persons selected in order to include a variety of people as regards age, gender, impairment and assistance organisations (e.g. private firm, user-cooperative and municipality). The users who contented to participate through the questionnaire were underrepresented by men and users with the municipality as assistance organisation. In order to increase the variety in the final sample, we sent out invitations to 20 men with the municipality as organisation. 4 users contented to participate and we selected the 2 users who best complemented the other 10, regarding diversity in age and impairment.

Information about the interview was mailed to the 12 users and they were free to decide the time and place of the interview. The data collection was undertaken between June 2005 and October 2006. Ten interviews were conducted in the homes of the users and two interviews took place at the Department of Psychology, Göteborg University. Three users were not able to participate in the interview fully, due to their impairments. In these cases, we have involved "*significant others*" (Tøssebro, 1998). The "significant others" have been instructed to only consider the perspective of the user they represent. In two of the three cases, the users have been able to participate and the "significant others" (mother and personal assistant respectively), were asked to act as an interpreter. In one interview participation was not possible and the user was only represented by a "significant other" (mother).

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 Agency.

Procedure

A qualitative interview was conducted as an everyday conversation in which the user was encouraged to talk freely (Mishler, 1986). The main questions were: “In your opinion, what does the concept personal assistant imply?”, “What are important characters of a personal assistant?”, “What is characteristic of a bad assistant?”, “What is characteristic of a good assistant?”, “Do you find your assistants lacking in any way?”, “How do you perceive quality concerning personal assistants?” This type of question invites participation and narration. The questions overlapped and were only brought up if the first question and the following conversation did not cover them. More abstract questions about bad and good assistants were combined with concrete questions related to critical incidents. A critical incident can be described as an incident that makes a significant contribution - either positively or negatively - to an activity or phenomenon (Bitner, Booms & Tetreault, 1990). We asked the user to tell stories about experiences they have had with good and bad assistants. Some users also exemplified bad and good assistants through critical incidents, without any questions from us. The interview questions were adapted to the individual’s ability to respond (e.g. some respondents prefer to talk in concrete terms of good and bad assistants, while others could relate to more abstract attributes of quality concerning personal assistants more easily). The interviews lasted between 45 and 80 minutes. The data was collected in the same time as data to a related study (Roos, 2009).

Data Analysis

The interviews were audio recorded, transcribed verbatim and analysed through content analysis (Kripendoff, 1980; Smith; 2004; Berg, 2004; Schilling, 2006). The text was first divided into *meaning units*; transcribed verbal expressions whose content corresponded to what the users desire of their personal assistants. Each meaning unit was then *condensed* to its basic content by deleting all unnecessary linguistic expressions and transforming its content into a short form. Thereafter, the condensed meaning units were *coded* and similar codes were grouped together into categories (Schilling, 2006). The development of categories was derived through a *bottom-up process*; from inductive inference concerning coded, condensed meaning units (Smith, 2004; Berg, 2004). The category system, with subcategories and categories, was built through the questions: What desired attribute of a personal assistant is this about? What other attributes are like this attribute? What distinguishes this desired attribute of a personal assistant from other desired attributes of a personal assistant?

Since the narratives yielded rich and complex information, the categories are illustrated using representative interview quotations (Smith, 2004). To facilitate comprehension, the users' spontaneous oral utterances have been rendered into a readable, written form. (Kvale, 1996).

Two authors (JMR & ATJ) with different academic backgrounds agreed that the categories have been created correctly in accordance with the methodology we have been using. The third author (EH) has independently investigated the interview texts and the categories and confirmed that no data related to the aim of the study has been excluded from the interview texts due to lack of a suitable category.

Findings

The analysis of the interviews resulted in a taxonomy of ten attributes that the users desire of their personal assistants (Table 1).

[Insert Table 1 about here]

Discreet

A discreet assistant keeps a low profile and does not draw attention to her-/himself. The discreet attribute of an assistant can be related to the user her-/himself or to the user when he/she meets other people.

Related to the user alone

A discreet assistant is tactful and approaches the user’s home carefully, without drawing improper attention to her-/himself: ”An assistant does not go straight to the living room and put her/his feet up”. A discreet assistant is also able to handle emotional reactions from the user without becoming personally involved. If the user is unhappy or irritated, the assistant has to accept this and leave the user alone.

Related to the user and a third person

In shopping situations, shop assistants sometimes talk to personal assistants instead of users. Tactful assistants ignore such shop assistants, making themselves more or less invisible. A discreet assistant also stays in the background when the user meets friends and family:

> When a friend and I have a conversation, it is between the two of us. It is not a three-part conversation, between me, my friend and my assistant. If we think that Freud was a biologist, for example, and my assistant knew he was a psychologist, she should not correct us in spite of this.

Sometimes the assistants are involuntarily drawn into a conversation. In such undesired situations, the assistants must be loyal to the user’s point of view.

Obedient

An obedient assistant does not hesitate to act as the user tells her/him to. Obedience can be task related or process related.

Task related obedience

Task related obedience is when the user only dictates what he/she desires, e.g. “clean the bathroom”, “clean the windows”, “read a story” or “bake a cake”. Task related orders are common when the user does not know the procedure. A disobedient assistant opposes the desire of the user and refers to personal opinions or general rules: “When I was going out for a while, I asked the assistant to bake a cake. She refused, maintaining that such activities were not covered by the Assistance Benefit Act. “

Process related obedience

Process related obedience implies that the user explains every step in detail to guarantee that it will be accomplished as if the users had done it by her-/himself. One user with a palsied hand expressed process related obedience in the following way:

> I can not live with a person who questions my way of doing things, someone who prefers to do my things in their own way instead. The assistants are my right hand, and they should do things in the same way as my right hand would!

The user desires process related obedience when the user has expert knowledge about a specific process (e.g. cooking an advanced dinner).

Reliable

A reliable assistant is someone the user can trust to work hard and well. A reliable assistant will always act and behave in the way the user wants her/him to. Such an assistant follows judicial and implicit agreements.

Follows judicial agreements

A reliable assistant understands and follows client confidentiality laws and time schedules. If an assistant is unable to work for one reason or another, it is necessary to inform the user as soon as possible.

Follows implicit agreements

Many agreements between the user and her/his assistants are built on mutual confidence instead of laws. The user must trust the assistants to execute tasks efficiently and carefully. If an assistant is inefficient, the user will be delayed in her/his everyday life. If the assistant is not careful, the user must control the assistant all the time: “I need some things for my living. I must trust that the assistants pack those things every time we are going outside, I do not want to control them”.

Informative

An informative assistant is able to communicate useful information to the user and to other assistants.

Communicates useful information to the user

An informative assistant is able to communicate what is going on, for example what the assistant is doing when the assistant is washing the user’s body. An informative assistant should also communicate things that are hard for the user to discover: “I would like the assistants to inform me if they take the last things from the fridge, or if it is dirty somewhere, or if my sweater is not tucked into my trousers”.

Communicates useful information to other assistants

To create a stable environment for the user, it is important for the assistants to communicate with each other, so that they perform routine tasks in the same way.

Alert

An alert assistant provides help or takes action if it becomes necessary. Two aspects – ready to step in and stand-by function – are used to describe an alert assistant. The first is related to initiatives taken by the assistant and the second is related to initiatives taken by the user.

Ready to step in

An assistant who is ready to step in observes the user when he/she performs different kinds of activities. Such an assistant stays in the background as long as possible and only steps in when the user can not manage a specific task (e.g. cut onions when making meatballs). An alert assistant might also guarantee health related security, for example be attentive and ready to act correctly and promptly when the user has an epileptic seizure.

Stand-by function

The user sometimes wants to keep a distance to her/his assistants (e.g. when the user is in a work meeting, visiting a doctor, meeting a partner etc.). However, the assistant must still be ready to act if necessary. This aspect of alertness is like a stand-by function of a monitor. The user takes the initiative to contact the assistant for support and the assistant must quickly change from “being passive to being very active”:

> I can spend two hours in a meeting. The assistant is waiting in another room and the only task during two hours is to be available. But, suddenly I have a ten minute break. During this break the assistant has to do a lot.

Respectful

A respectful assistant shows respect for the user. Respect consists of two aspects, the assistant should respect the user as an equal human being and the assistant should respect the user for the person he/she is. The first aspect seems to be a prerequisite for the later aspect.

Respects the user as an equal human being

This aspect is related to the assistant's general values about people with disabilities: "Assistants must look beyond the handicap and view the disabled person like another human being". The assistant should respect the user as a human being who thinks and acts in a proper way. If two assistants are working together, they must respect the user as an equal human even if the user is not able to communicate. If the assistants are discussing the user's privacy above the head of the user, the user may develop thoughts that are difficult to express. Such thoughts create anxiety and irritation. If the user is able to tell the assistant that he/she would like to do something her-/himself, the assistant should respect that instead of saying: "no, I would like to help you". If the user needs assistance to think and act in a proper way, the assistant must correct the user in a respectful way: "Should you not have another think about this matter and do it in another way?" Assistants should respect the user's privacy and understand that the user prefers to be alone in some situations (e.g. when the user takes a shower or when the user meets family and friends). A respectful assistant also shows respect in meetings with third persons. One user had the following experience with an assistant who did not respect her as an equal human: "We bought coffee and the waitress asked if we were in the same party. My assistant answered no, she explained that she was my personal assistant. This situation was very embarrassing. I was not viewed as a fellow being."

Respects the user for the person the user is

The second aspect of respectfulness is related to unique values of the specific user. It is important to understand who the specific user is. For one user the most important thing is to be respected as an adult person, who knows what she is talking about. She explains that the assistant acts like a mother who always butts into her life: "you should not be in bed", "you should not touch that object", "you shouldn't eat sweets" etc. For another user, it is more important not to be discriminated against because of medicines, epilepsy or being in a wheelchair. He views a respectful assistant as a person who dares to yell at him even thought he/she is aware that this might lead to the user getting into cramps. This user would like to be yelled at if he has done something wrong. Should the assistant not yell at him, he/she is primarily thinking of the consequences of the scolding and not about the person the user is. For a third user, self-determination and empowerment is very important:

> The assistant should let me live my life in my way. For example, if I decide to walk in the middle of the road instead of the pavement. Such an example might seem ridiculous, but for me it is important. It is about trust, that I can judge risks by myself. If I decide to take a risk, I decide to take a risk.

Considerate

A considerate assistant pays attention to the user's needs, wishes and feelings and is kind to the user. Such an assistant is concerned about the user and is intrinsically motivated through the user's well-being: "such an assistant becomes happy if the user is happy". Characteristics of a considerate assistant are that he/she (1) focuses on the user, (2) makes efforts to understand the user, (3) encourages the user and (4) is responsible for the user.

Focus on the user

An assistant who focuses on the user puts the user first and spends all her/his energy on the user. An assistant who is totally focused on the user "leaves his own wishes and needs outside the door". An inconsiderate assistant focuses more on her-/himself than on the user, which might prevent the satisfaction of the user's needs. One user had the following experience of a self-focused assistant: "We were eating together, the assistant and me. The assistant was busy eating himself and forgot me completely. The assistant had basically forgotten what the job is about". Self-focused assistants may carry out activities (e.g. driving, walking etc.) without considering the user's physical status. They may act independently instead of considering the user's right of self-determination (e.g. to cook, to control the music etc.).

Makes an effort to understand the user

To serve the user in a proper way the assistant has to make efforts to understand the user. If the assistant is uncertain, the assistant should ask the user about his/her opinions. Such questions are important before, during and after a specific action.

An assistant who asks many questions shows that he/she really considers the user. The way of asking questions should be related to the user's ability to answer. A mother of a user with an *intellectual disability* (Tøssebro, 1998) exemplifies how an assistant might be considerate toward her son:

> It is easy for an assistant to just serve John one kind of porridge in the morning. But, he has three choices; oats, semolina and Graham's porridge. John is only capable of saying yes or no, which implies that the assistant must mention all alternatives. A very considerate assistant will also ask John if he would like to mix different kinds of porridges, for example oats and semolina.

Sometimes it might be hard for a user to know what he/she needs. An assistant can make efforts through trying different kinds of products and activities. For instance, the rocking chair became very popular for one user, but before she tried it she did not know what it was.

Encourages the user

An assistant who encourages the user pushes the user to do things (e.g. physiotherapy and outdoor activities). Such an assistant, for instance, encourages the user when the user is sad for one reason or another:

> Nowadays there are a lot of barriers in my life. For example, if we are going out for a dinner. I used to be a very active person and my body was fit. I could be dressed in a beautiful way. Nowadays, my self-image is different. I do not

> like myself today. It is possible for the assistant to spur me in the right direction, for example through arranging a dinner for some friends.

Be responsible for the user

The assistant should be responsible for the user when the user is not able to take care of her-/himself. Such a situation might be when the user lacks the necessary insight to be able to make a proper decision. The user sometimes wants the assistant to make decisions if the topic is unfamiliar. One user describes when he went to school with a high temperature: “It would have been better if the assistant had told me to stay at home”. Another user explains how an assistant had persuaded him to contact a doctor and thereby saved his life. A mother of a user with an intellectual disability states that it is sometimes necessary to make decisions for the user:

> When it is winter and cold outside, there is no point asking him if he wants his jacket. He might say no, because he is not capable of understanding what is best for him. In such a situation, it is better to just dress him.

Friendly

A friendly assistant is kind and acts like a friend towards the user. A friendly assistant is someone the user can talk to and together with whom the user can do things. A friendly assistant also views the relationship as friendship rather than as a social work relation.

Talks to the user

Sometimes the user would like to sit down and talk to the assistant like a friend. Such an assistant must be willing to be open toward the user. It is important that the assistant tells the user about her/his own life, and not only the other way around: “I would like the assistants to tell me about trips they have done, if they have worked abroad. I would like to hear about their lives, I don’t like to just talk about myself all the time.”

Performs activities together with the user

A friendly assistant wants to perform activities together with the users. Such activities may be doing cross-words, playing cards, watching films, eating at restaurants etc.

Views the relation between user and assistant as friendship

An assistant who views the user as a friend is not primarily thinking about formalities such as specific tasks or specific working hours. Rather he/she is thinking of the user as a friend who he/she would like to support. One user explains this in the following way: “If the female assistant is unable to do something, and it’s a job that takes a man to do, than she calls her husband, and he supports me as a human being”.

Pleased

A pleased assistant is satisfied with the user, the profession and life in general.

Satisfied with the user

An assistant can not do a good job as a personal assistant if he/she does not like the user. Such values are reflected in the assistant's behaviour: "It is very easy to say something, but when the assistant acts, then you know what the assistant really thinks".

Satisfied with the profession

An assistant must be pleased to work as a personal assistant. The assistant must view the job seriously and not just work for money.

Satisfied with life in general

The assistant must be pleased with life in general in order to perform her/his duties to a high standard: "A pleased assistant has a meaningful life; needs something more than sleep and food."

Practical

A practical assistant successfully deals with concrete tasks in the user's real life. Such tasks might be related to basic needs as well as general housekeeping.

Takes care about the user's basic needs

A practical assistant has the right attitude and the knowledge required to efficiently deal with the user's basic needs. Examples of the required knowledge to do the job might be how to lift the user, how to change the user's clothes, how to change the user's nappy and/or to bottle the user's urine. If the assistant is practical, the user feels secure that her/his basic needs will be satisfied in a comfortable way. One user describes a situation when the assistant could not change the nappy: "The assistant put me to bed and noticed the nappy was wet. He couldn't handle a dirty nappy so he left".

Handles general housekeeping

A practical assistant successfully deals with general housekeeping (e.g. vacuum-cleaning, washing up and cooking). One user explains that he takes such knowledge for granted:

> If I ask them to vacuum-clean, I should not have to tell them how the hell they should do it. Or mop up the floors. That is not my job. If they do not know how to do these things, they will have to go somewhere else to learn, because I do not have the energy to be that kind of human manager, it is not my job.

Discussion and conclusion

Methodological trustworthiness

In qualitative research the concepts credibility and transferability can be used to describe different aspects of trustworthiness (Lincoln & Guba, 1985). In three interviews it was necessary to include "significant others". Not letting people speak for themselves threatens the credibility of the study (Tøssebro, 1998). We do not know if the data from "significant others" correspond to the true attributes that users desire from their personal assistants. However, the alternative would have been to exclude those users from the study and thereby threaten the study's transformability (Lincoln & Guba, 1985). Since our aim is to find attributes which are applicable and consistent among adult users with severe disabilities in general, we needed to choose different kinds of users and thereby increase the possibility of shedding light on a variety of desired attributes of personal assistants (Patton, 1987).

Probably some attributes are not transformable to personal assistance in other countries. According to Zeithaml, Bitner and Gremler (2006), the desire of a service can vary widely depending on reference point the customer holds. We believe that the Swedish system, as part of the welfare state idea, creates great expectations among the users. In Sweden, users' expectations are partly shaped by the fact the service is made possible through governmental resources. In societies with less support from the government, the users' desires of assistants might for instance be more focused on practical support related to basic needs, and less focused on friendly assistants who performs leisure activities together with them.

Discussion of the findings

The importance of a specific attribute of personal assistants depends on the specific user. For instance, some users would like the assistant to be a "best friend" while some users think it is important that they do not have a personal relation to their assistants.

The importance of an attribute also depends on the specific situation for a specific user. A personal assistant should be able to balance different kinds of attributes in different kinds of situations. To promptly combine different attributes, the assistant must be able to take the user's perspective, as one user said: "The assistant must be able to enter my world, to crawl into my shell". An assistant must balance between situations when the user desires closeness and situations when the user would like to distance her-/himself from the assistants. In some situations the assistant should be friendly while the assistants in other situations should almost disappear and become invisible. According to some North American users, the best personal assistants are those whose presence is barely felt: "When the workers are invisible, consumers can feel that they have accomplished their daily activities by themselves" (Rivas, 2004, p. 75). To create a feeling of independence, the assistants have to be discreet and obedient. But at the same time, they also have to be alert to provide help and take action if it becomes necessary. If the assistant is not alert, the feeling of independence can suddenly be replaced by a feeling of helplessness.

The ability to balance between different attributes is also obvious when it comes to empowerment. The dilemma will be how much the assistant should "take over" instead of respecting the users' right to self-determination. Hawks (1991) distinguished between "power over" and "power to". "Power over" means controlling others without caring about them, while "power to" means doing things together or making things possible for others. In some situations, when the users are unable to make a proper decision, the users would like the assistants to make decisions for them. In such a situation the user desires a considerate attribute rather than an obedient attribute. However, if the assistant takes decisions for the user, the assistant must act with respect and care for the user and not take control of the user's life. Psychological empowerment is seen as giving individuals a greater sense of personal control over their own lives (Hogg, 1999). The role of the assistant seems to be to empower (give power to) the user and thereby overcome the disability that otherwise can prevent the user to reach her/his full human potential. It is worth noting that this conclusion, about support to people with disabilities, is neither unique for our time nor the Swedish society. Already in 1951, Laswell stated that "positive aid is made available in order to overcome handicaps that would otherwise prevent the achieving of a full human experience" (Laswell, 1951, p. 477). We think that personal assistance, as described in the Swedish law, is in line with this view. However, assistance as a legal right is not enough. The present study shows that some personal assistants, due to lack of respect for the user, prevent the user to overcome the disability. One user explained that lack of respect and lack of power for people with disabilities are deeply rooted in the structure of our society:

> Come back in 200 years. There is a long way to go. There is a very long process. There is an inequality from the beginning, between me and my personal assistants. It is about the perspective of a majority on a minority. But it is also about our perspectives on ourselves, as a minority.

Concerning the social work ideals described in the introduction, most of the desired attributes in this study corresponds to the service ideal. The user only desires attributes that correspond to the rehabilitation and care ideal in exceptional cases (e.g. considerate assistants who encourage the users and take responsibility for the users' health). We have also found a new dimension of a personal assistant, that we have not been able to find explicitly described in previous research; the assistant as a friend. The friendly attribute goes beyond the social work ideals. However, despite that previous researchers (e.g. Allen & Ciambrone, 2003) not explicitly discuss personal assistants as friends, they have found that companionship and intimacy influence the quality of life for people with disabilities more than practical assistance. According to Allen & Ciambrone (2003), a personal assistant must therefore meet multiple needs, of both instrumental and emotional nature.

According to Hugemark & Wahlström (2002), a user would sometimes like the assistant to take her/his own initiatives, which corresponds to the care ideal. This attribute seems to be the opposite of the obedient attribute we have found. An assistant who takes initiatives of her/his own accord acts independently, according to her/his own ideas. Hugemark & Wahlström (2002) also describe a risk related to assistants who take own initiatives, that they are taking over the life of the user. In the present study, some users would like their assistants to know them so well that it becomes unnecessary to use verbal communication. However, the users do not mean that the assistants should take their own initiatives, rather that they should be able to "read" the initiative of the user in the user's mind. According to the users, such ability takes a very long time to develop and before the assistant can take the perspective of the user, the assistant must be obedient and act as the user tells. To explain the ability to take the user's perspective, users refer to abstract terms such as "empathy", "social competence" and "common thoughts".

One user said; “I do not know what the assistant does. It is an ability some people have, that they just feel what the user wants”.

One theory for explaining how infants develop the skill to take the perspective of their mothers is that they first imitate their mothers without understanding what they do (Charpendale & Lewis, 2004). It is possible that the work of an assistant is coordinated with the desire of the user before the personal assistant understands much about the user. The process by which the infant shifts from participating in interactions to an understanding of the distinction between her/his own and other’s intentions remains a holy grail within this area of theorization (Charpendale & Lewis, 2004). We seems to meet a similar problem, we are not able to describe the process whereby an assistant shifts from being a social worker who just executes orders to a person who understands the world of the user. We think that an assistant must be respectful and considerate in order to interpret verbal language as well as reading bodily communication including facial expressions and gestures. To be able to take the perspective of the user, we also think it is helpful if the assistant is pleased with the user, the job and life in general, so that the assistant will work with the user for a longer period of time. Furthermore, to be able to take the perspective of the user in all different situations, the assistant must also be alert to act in all different situations.

According to Holm (2001), empathy is the ability to understand the feelings of other persons. Empathy consists of both a cognitive and an affective component. The cognitive component may be explained through self-reflection, observations and theoretical learning. The affect component is harder to explain: “A repeated change must occur, between observation, perception of feeling, new observation and reading of the feeling – most of it at a preconscious level" (Holm, 2001, p. 73).

Lok and McMahon (2006) have a similar perspective; they state that the ability to take the perspective of another person comes from a cognitive capacity as well as an emotional capacity. It is possible that different users desire more or less of their assistant's two capacities. Users with physical disabilities state that *inquisitive* (Lok & McMahon) assistants will learn to take the perspective of the user: "After a while, the assistant does not need to ask me what I desire. The assistant should know what I desire". In contrast, assistants of users with intellectual disabilities seem to need a more emotional capacity. As one mother said: "She laughs when she is happy and she cries when she is unhappy, the assistants must interpret everything between those emotional states."

The challenge to explain the ability to take the perspective of another person goes far beyond this study and has been and still is the object of a considerable theoretical debate (Carpendale & Lewis, 2004; Lok & McMahon, 2006; Sharp, Fonagy & Goodyer, 2006).

From previous research we know that optimal personal assistants meet multiple needs of an instrumental and emotional nature (Allen & Ciambrone, 2003). In this study, we identified ten specific desires. Our conclusion is that an assistant who is able to take the user's perspective embodies the attributes the specific user desires and balances those attributes according to situational demands. It remains to understand which users desire what kind of attributes, in what kind of situation.

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Table 1

Categories and subcategories of attributes the users desire of their personal assistants

Category	Subcategory
Discreet	Related to the user alone
	Related to the user and a third person
Obedient	Task related obedience
	Process related obedience
Reliable	Follows judicial agreements
	Follows implicit agreements
Informative	Communicates useful information to the use
	Communicates useful information to other assistants
Alert	Ready to step in
	Stand-by function
Respectful	Respects the user as an equal human being
	Respects the user for the person the user is
Considerate	Focuses on the user
	Makes an effort to understand the user
	Encourages the user
	Be responsible for the user
Friendly	Talks to the user
	Performs activities together with the user
	Views the relation between user and assistant as friendship
Pleased	Satisfied with the user
	Satisfied with the profession
	Satisfied with life in general
Practical	Takes care of the user’s basic needs
	Handles general housekeeping

II

Running head: QUALITY ATTRIBUTES OF EXTERNAL ASSISTANCE PROVIDERS

What do people with disabilities desire from their service organizations of personal assistance?

John Magnus Roos, Anna-Lisa Thóren-Jönsson and Erland Hjelmquist
University of Gothenburg

Correspondence:

John Magnus Roos
Department of Psychology
University of Gothenburg
Box 500
SE – 40530 Göteborg.
Phone: (voice) +46 31 786 1641, (fax) +46 31 786 4628
E-mail: magnus.roos@psy.gu.se

Abstract

The present study investigated what adult users of Swedish personal assistance desire of their service organizations. Qualitative analysis of interviews with 12 users resulted in five categories: (1) Have a proper ideology of personal assistance, (2) interact with the user in a service-minded way, (3) mediate between users and personal assistants, (4) provide good work conditions for personal assistants and (5) represent the user politically. The results were discussed in relation to theories of customer desires. The second category corresponds to desires of service customers in general, while the other categories are more specific for personal assistance.

Introduction

According to Swedish law, personal assistance refers to personally designed support that is provided by a limited number of persons (personal assistants) for persons (users) who, owing to major and lasting impairments, need assistance with their basic needs (e.g. personal hygiene, meals, dressing and communication). Personal assistance should promote equality in living conditions and full participation in the life of the community for users. The aim of personal assistance is to give users the possibility to live as others do (Act 1993:387; Act 1993:389). There is no correspondence to the Swedish assistance service in any other country (Andén, 1995; Askheim, 2005). The Swedish system of personal assistance 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. The Swedish system also gives the users much more influence over the assistance received than any other system (Askheim, 1999, 2005).

The breakthrough for the arrangement of personal assistance in Sweden is dated to 1994, when two particular acts came into force: "*Act (1983:387) concerning Support and Service for Persons with Certain Functional Impairments*" and "*The Assistance Benefit Act*". Those acts implied that personal assistance was established as an individual right for users who qualified for the service (SOU, 2005:100). According to the Act (1993:387), users qualified for personal assistance comprise three different categories of people (Table 1).

[Insert Table 1 about here]

There is no lower age restriction for when personal assistance should be provided, but the user must have been granted assistance before the age of 65 (Act, 1993:387). The Swedish Social Insurance Agency's officers decide on assistance allowance if the user needs personal assistance for her/his basic needs for an average of more than 20 hours per week. This is regulated in the "Assistance Benefit Act". If a user needs assistance 20 hours per week or less, the municipality takes the decision on assistance allowance. This is regulated in the "Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments". The municipality is always financially liable for the first 20 assistance hours per week (Act 1993:387; Act 1993:389).

This study will only consider users who have personal assistance according to the "Assistance Benefit Act", in other words users who have personal assistance for basic needs for more than 20 hours a week. If this criterion of basic needs is fulfilled, the person may receive personal assistance with a wide range of tasks in areas such as working life, leisure activities, cleaning and many other areas (Grönvik, 2007). Users who receive assistance according to the "Assistance Benefit Act" account for two-thirds of the total number of the Swedish users of personal assistance (total number 15 000) and they are in need of the most comprehensive assistance (Askheim, 2005).

The "Assistance Benefit Act" contains regulations relating to the distribution of public funds for the cost of personal assistance. The act does not regulate the practical provision of personal assistance. The act is written in order to give the user influence over how the support should be provided. 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 organisation or by both employing assistants her-/himself and receiving assistance through the municipality or another assistance provider (Swedish Social Insurance Agency, 2007). Almost all users (>96%) delegate the employer's liability to an External Assistance Provider, EAP (SOU 2005:100). There are three different kinds of EAPs; municipality, cooperatives and private firms. For simplicity, we can view the user as a customer who receives a cheque from the government for which he/she can buy the assistance he/she desires (Norén, 2000).

All EAPs are formal employers of their assistants. They are responsible for working conditions, according to Swedish law, varying from working environment to sick leave. In general they also manage financial administration and recruitment of their personal assistants (Norén, 2000). The basic difference between different kinds of EAPs is the view of personal assistance. Personal assistance for the municipality 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 centralised for the municipality while they usually are decentralised to the specific user in the case of a cooperative or a private firm (Norén, 2000). Users who arranged their personal assistance through the municipality had less influence and self-determination regarding the people who were actually working as their personal assistants and the tasks they were assigned. 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 EAP's work and there are no legal barriers to enter the market (besides the general legislation, e.g. the Swedish Companies Act, the Association Act etc.). Instead of providing obligations, the parliament encourages the EAPs to listen to the desires of their specific users and independently adapt their assistance. This implies that the quality standards among different EAPs might be different and sometimes contradictory (Hugemark & Mannerfelt, 2003).

The present study strives to give a view of the users conceptions of desired attributes of their EAPs, irrespective of the variation in the frame factors related to specific instructions. On the basis of direct observation or information received from outside sources or by way of various inference processes, a person associates an object with a number of attributes. In this manner, the person forms beliefs and attitudes about himself, about other people, about institutions, behaviours, events etc. (Fishbein, 1975). The aim of the present study is to investigate what attributes adult users of personal assistance desire from their EAP. To improve services, researchers must ask people with disabilities what they desire from a specific service (Gough, 1994; Söder, 1995; Lutz & Bowers, 2005).

Method

Participants

The sample consisted of 12 adult users≥(18 years), 8 women and 4 men. The participants ranged in age from 21 to 65 (mean age 47 years). The EAPs were distributed as follows; 3 users of municipality, 4 users of cooperatives and 5 users of private firms. All users lived in the area of Gothenburg. The time during which they had been recipients 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 (224 assistant hours per week means that the user has at least two assistants during some hours), mean 118 hours per week.

Procedure

Users who had already participated in a related quantitative study were asked to complete a questionnaire (Roos, 2003). In the questionnaire the informants were asked if they were willing to participate in an interview. The questionnaires were mailed to 291 users, who were randomly selected from the total populations of 474 users who received assistance according to the ”Assistance Benefit Act” in the area of Göteborg in April 2003. The questionnaire was filled in and returned by 72 users (Roos, 2003). A total of 27 users consented to participation in an interview and among those, 10 users were selected in order to represent the wide spectrum of users as regards impirment, EAP and demographic characters (age and sex). The 27 users were underrepresentative of men and users who had the municipality as EAP. In October 2006, an invitation was therefore mailed to 20 men with the municipality as EAP. Four users consented to an interview and among those two were selected in order to increase the diversity among participants.

Information about the interview was mailed to the 12 users and they were free to decide the time and place of the interview. The data collection was undertaken between June 2005 and October 2006. The data was collected in the same time as data to a related study (Roos, 2009). Ten interviews were conducted in the homes of the users and two interviews took place at the Department of Psychology, Göteborg University. Three users were not able, due to their impairments, to fully participate in the interview. In these cases, we have involved “significant others”. The most common alternative to subjects speaking form themselves, is to ask “significant others” (e.g. social workers or parents) to represent the subjects (Tøssebro, 1998). The “significant others” were instructed to only consider the perspective of the user they represent. In two of the three cases, the users were able to participate and the “significant others” (mother and personal assistant respectively), were asked to act as an interpreter. In one interview participation was not possible and the user was completely represented by a “significant other” (mother).

Interview

A qualitative design was chosen since it allowed the users to describe their views and experiences in their own words and raise issues which were important to them. 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 an EAP?", "what is characteristic of a bad EAP?", "what is characteristic of a good EAP?", "do you find your EAP lacking in any way?", "how do you perceive quality concerning an EAP?". 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 EAPs from their own experiences. Further, we asked the users who had changed EAP (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 & Tetreault, 1990). Critical incidents can also be positive. Several participants used positive incidents to describe desirable attributes of an EAP. The interview lasted between 45 and 80 minutes. The interviews were audio recorded and transcribed verbatim before the analysis.

Analysis

Content analysis was performed (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 EAP. 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 refers to category as a group of content that shares a commonality and answers the question “What?” (Krippendorff, 1980). We created 19 sub-categories through the questions; “what attribute desirable in an EAP 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 (Graneheim & Lundman, 2004).

Since the narratives yielded rich and complex information, the categories are illustrated using representative interview quotations (Smith, 2002). To facilitate comprehension, the users spontaneous oral speech have been rendered in a readable, written textual form (Kvale, 1996, p. 267). In order to offer the reader an idea of how salient the categories are, we have counted the number of users falling within each of them (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 Agency.

Results

The analysis of the results revealed 19 sub-categories of attributes the user desires of their EAPs. Those 19 attributes were possible to cluster in five categories; (1) having a proper ideology of personal assistance, (2) interaction with the user in a service-minded way, (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 2 shows the categories, the sub-categories and their frequencies.

[Insert Figure 1 about here]

[Insert Table 2 about here]

Having a proper ideology of personal assistance

Users of personal assistance explain that it is important that their EAP has a clear ideology of what personal assistance is and how they should practice personal assistance: "The EAP 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 organisation". The ideology of personal assistance goes beyond specific actions, at the same time as the ideology of personal assistance should influence all actions directed to users, assistants and the society. The EAP'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 EAP has the user's well-being as first priority. The EAP's ideology of well-being of users must also correspond to the specific user's ideology of well-being for her-/himself. In other words, the assistance must be adapted to the needs of the specific user. According to the users, a proper ideology of personal assistance (1) follows the legal framework of personal assistance, (2) puts the users well-being first and (3) adapts assistance to the specific user's needs of assistance.

Following the legal framework of personal assistance

The EAP must follow the governmental instructions about what personal assistance is and what tasks are included in the assistant's work. According to some users, the EAPs lack knowledge of legal rules related to irregular working hours for assistants, expenses for user's travels and extra assistant costs. The EAP should distinguish personal assistance, which is regulated in the "Assistance Benefit Act", from home help service, which is regulated in "The Social Service Act":

> The EAPs 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

The EAP's representative must prioritize the well-being of the user instead of the well-being of her-/himself, as one user states:

> The most important thing is that the EAP must have 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 to understand is that a careless act on the part of the EAP's 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 EAPs to have a different ideology than general business organisations: "When greed exists, the assistance become businesslike. Greed in the form of money and materialism disturb the order, it is not humanitarian anymore. The service becomes worse and the EAP attracts the wrong kind of assistants."

Adapting the assistance to the specific user's needs of assistance

According to the users, it is difficult for one EAP to give high quality assistance to all the different users. Therefore, the EAPs are adapted to serve particular groups of users. The user's needs of assistance must correspond to the EAP's assumptions of their needs. The following two quotations illustrate different ideologies; "the EAP assumes that the user is independent" and "the EAP assumes that the user cannot speak for her-/himself" respectively. The users explain that ideological differences between EAPs imply different strategies for fulfilling the needs of their users. An ideology which is adapted to a specific group of users may therefore be maladapted for another group as illustrated by the following two quotes: “My EAP is not good for people with brain injuries” and “people with only physical disabilities desire something else of their EAP”.

Interacting with the user in a service-minded way

Nine attributes describe how the users would like their EAP to interact with them in a service-minded way ; (1) empowering the user, (2) caring about the user, (3) supporting the user when the user asks for a favour, (4) reducing the user’s workload related to personal assistants, (5) providing assistants in all situations, (6) providing a limited number of assistants, (7) arranging training for users/legal guardians, (8) arranging social activities for users and (9) covering extra costs related to personal assistants.

Empowering the user

The EAP’s representatives must give the user control over her/his assistance and hand the power over to the user. This implies that the EAP must let the user gain a great deal of insight into the coordination of her/his assistance. In order to have a level of self-determination, the user would like the representatives of the EAP to give clear and timely information about the recruiting process of new assistants. The user would also like to be kept informed as to whether an assistant is unable to work for one reason or another. The user would also like to 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 EAP regard the user as an equal human being who is responsible and reflective. One user states:

> I can feel that the EAP has a disparaging attitude toward the user. 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 EAP view me as a fusspot who can speak for myself.

A representative of an EAP 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* (Tøssebro, 1998) describes a situation when the representative took over too much as follows:

> She 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, she just put the paper on the desk and tapped the dotted line twice. She said "sign it, you have to sign it", instead of explaining what it was about.

To better understand the user's perspective of empowerment, the users state that the EAPs need to listen more to the users and recruit more representatives who are receivers of assistance themselves.

Caring about the user

A representative of the EAP who cares about the user takes an interest in the user and shows the user appreciation. The representative's care implies that he/she makes efforts to have a dialogue and a personal relation with the user (e.g. through home visits, telephone calls and mails). Such a person pays attention to the user's specific needs and takes initiative to satisfy them. One man put it like this: “If it were not for a home visit by a contact person from my EAP, I would not have this wheelchair. The person saw my old model and informed me about a more modern and suitable wheelchair”. A woman who felt that the representatives of the EAP did not care about her enough described her thoughts in the following way:

> In the past, a representative of my EAP always passed by with a present for Christmas, which in itself is very nice. But last Christmas, the EAP sent the present and seasonal greetings through a personal assistant. I would like the contact person to wish me a Merry Christmas herself, at least on the telephone. It was neither about a present nor seasonal greetings. It was about being treated as a valuable person, that I was somebody. I feel sorry that the she did not understand better.

Supporting the user when the user asks for a favour

To support the user efficiently the EAP must be available and provide representatives that are both motivated to support the user and competent enough to give appropriate support. Being available is a necessary condition to serve the user on demand. The EAP can be available through a favourable location of their offices and through good telephone service. A motivated representative of the EAP acts when the user, for one reason or another, asks for a favour. The representative should be sympathetic and view the user’s contact seriously. One user had bad experiences with an unmotivated representative:

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

A competent EAP provides expertise such as legal assistance and medical care. Such an EAP is able to support the user in potential conflicts with the Swedish Social Insurance Agency considering the number of assistance hours or if a personal assistant suffers an accident while working.

Reducing the user's workload related to personal assistants

The user would like their EAP to reduce her/his workload related to personal assistants. This implies that the user would like the EAP to support her/him in the recruiting process of new assistants and support her/him during different meetings with her/his assistants. One man 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 persons] 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

It is important that the EAP can provide assistants that suit all situations (e.g. all times, all places and all activities). Some users need assistance during the night and it is important that the EAP can provide assistants 24 hours a day. One user states: "I changed EAP because my previous EAP could not guarantee assistants during the night". Some users also live in distant places and the EAP must therefore find assistants who are willing to work there. If the user suddenly decides on an activity (e.g. go to their summer house or take a drive), it is important that the EAP can provide appropriate assistants at short notice. In some cases it is also necessary to provide two assistants at the same time. If an assistant quits her/his job, the EAP must provide a new assistant immediately.

Providing a limited number of assistants to the specific user

The EAP 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 EAP distributes them to all users. It is terrible not to know who is working tomorrow morning".

Arranging training for users/legal guardians

Users desire training for the purpose of improving their relations with their personal assistants. For users with legal guardians, the EAP should arrange training for the guardians. They should be trained in order to represent the user in a better way.

Arranging social activities for users

The users would like their EAP 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 with the same EAP.

Covering extra costs related to personal assistants

The user would like their EAP to provide them with 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. a chair for assistants). The EAP should guarantee such goods automatically, as one man said "When I need something, representatives of the EAP should pass by and give me kitchen paper, coffee and serviettes".

Mediating between users and personal assistants

The users would like the EAP to mediate between the user and the assistant through; (1) personal meetings and (2) by handling conflicts between the user and the assistants. 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 EAP handles conflicts if and when the relationship with the assistant is not satisfactory, for one reason or another.

Arranging meetings

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

Handling conflicts between the user and the assistants

It is important that the representatives of the EAP act as soon as they know about a conflict between the user and the assistant. A man described the EAP’s role in handling a conflict as follows: “I have neither the strength nor the desire to handle a conflict between myself and my assistants. It shouldn’t be up to me, it is the EAP 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 representatives of the EAP must be perceptive as 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 a representative of the EAP about a conflict. Wishes concerning how conflicts should be handled vary between different users. Some users would like the EAP to speak with the user and the assistants separately first, and then arrange a joint meeting, while some users would like their EAPs 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 EAP to do for their personal assistants; (1) arrange training, (2) provide good administrative conditions of employment, (3) arrange supervision and (4) provide rules and instructions for personal assistants.

Arranging training for personal assistants

Users desire that the EAP 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

The EAP should provide good employment conditions for their personal assistants, with decent monthly salaries and proper leave entitlement. The administrators of the EAP should also transfer the salaries in a proper way. If the EAP provides good conditions for their assistants, the assistants will stay for a longer period of time and provide better assistance for the user. As one user stated:

> The EAP must have good conditions for the assistants. The EAP 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

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 EAP 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. A woman describes a situation where she wanted her EAP to give her 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, they should have had support from the EAP, 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

The user perceives the “Assistant Benefit Act” as unclear considering the job description of personal assistants. Therefore the users would like their EAPs to provide rules for what the assistants are allowed to do and not to do. One user stated, “I would like the EAP to have more rules for personal assistants. I have heard that they sometimes carry paving stones in the garden. The EAP must clarify what you can expect from your personal assistants".

Representing the user politically

Some users would like their EAP to not only act in relation to specific users and assistants. The EAP should also act in relation to the society the user lives in and represent the user politically.

Being politically engaged on the behalf of the user

The EAP 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 EAP to work close to the government and the parliament and try to prevent reductions related to personal assistance. The EAP 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 representatives of the EAP to inform them about what is happening with personal assistance at the political level.

Discussion

Discussion of the findings

The present study describes what 12 adult users desire of their EAP. It is, however, worth pointing out, that the wishes of one user may very well be contradictory to those of another. Some users desire social activities for users as a group. Other users explain that it is impossible for the EAP to arrange something in common for users. Users who do not desire social activities for themselves do not view “disability” as a reason for companionship. Some users would like guidance to be available to the personal assistants, while other users are sceptical of the idea of requiring the assistants to receive guidance or supervision in any form. According to the sceptical users, personal assistants do not like supervision and will view it as “a further obligation”. Users are also sceptical toward supervision for personal assistants because users are critical toward the EAP’s ability to give professional supervision to their assistants. Some users ask for instrumental rules and instructions for personal assistants, while other users view it as a threat against their own right of self-determination. Instrumental rules and instructions for personal assistants are undesired because the users would not like to feel controlled by their EAP. Users would like their EAPs to treat them as judicious and responsible citizens, who themselves may define the rules governing the conduct of their personal assistants.

Sometimes, it is not enough that the EAP supply what the user associates with a successful EAP. The EAP must also adapt the desired attributes to the specific user’s need for personal assistance. For example, empowering the user is a complex attribute that must be adapted to the user's unique need for empowerment. The users' desire for self-determination and control in relation to the EAP may be related to receiving information in a respectful and timely manner when the EAP's representative executes different kinds of tasks for the user. It may also be related to the users being allowed to handle tasks themselves independently without improper meddling from the EAP. Power has been discussed as "power over" and "power to". According to Hawks (1991), "power over" is associated with control others, mainly without caring about them. The risk of strengthening those who are already strong is obvious. "Power to" is associated with accomplishing things together or making things possible for others, which seems to be in line with the users desire of their EAP, irrespective of her/his unique desire of empowerment.

The user of 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. Eight users desire a good interaction between the EAP and the personal assistants. Therefore, service production from the perspective of the user becomes more complicated than service production from the perspective of the general customer. We think that personal assistance is a more personally designed service than any other service. It takes a long time to learn to serve someone in a personal way (Grönroos, 2007). This implies that a number of ties will be developed between the user and the assistants (e.g. social bonds and knowledge bonds). Users are afraid of loosing their assistants because the assistants support them with such personal tasks that have a fundamental place in everyday existence, for example bodily hygiene (Chistiansen, 1994). We think that the users care about their assistants because they also have a lot of influence over, and responsibility for the service. Instead of governmental rules and regulations, the users receive an employer's liability for their assistants (Norén, 2000). If the users do not carefully consider the relation between the assistants and the EAP, they will risk the whole assistance reform because employment as a personal assistant would probably appear as unattractive (Ds 2001:72). It is possible that the customer perspective is too narrow when it comes to personal assistance. Underlying economic theories about customers are that customers act in their own self-interest and that customers therefore buy something in order to maximize the utility for themselves (Grönroos, 2007). As regards personal assistance, it is possible that the interaction between users and assistants is built on friendship rather than pure business and that the users care about the assistants' well-being for altruistic reasons.

Besides actions toward personal assistants, two users would also like their EAP to lobby for the users at a political level. Such a desire distinguished the users from general service customers described by Gummesson (1993). It is worth noting that the users who desire political achievements have cooperatives as EAPs, while the model of Gummesson (1993) is built on customers with private firms as service providers.

We think that viewing the user as a customer makes it easier to understand the large variation in attributes desired from the EAPs. Customers do not buy goods or services, they buy the benefits goods and services provide for them (Grönroos, 2007). 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 EAPs must provide support tailored to the individual's needs.

For a long period of time market analysts have used segmentation strategies to offer their customers individually tailored support (Grönroos, 2007). To develop a segmentation strategy it is necessary to measure attitudes (Kinnear & Taylor, 1996). To measure attitudes about an object, it is first necessary to identify the attributes that are linked to the object (Fishbein, 1975). In other words, this study is the first step in making explicit a range of attributes of personal assistance and thereby building the foundations for a more personally designed support.

Methodological trustworthiness

In qualitative research the concepts credibility, dependability and transferability have been used to describe various aspects of trustworthiness (Lincoln & Guba, 1985). To increase credibility we enabled users to express their views in the security of their home environments at a time that suited them. To avoid influences from a third person (e.g. a personal assistant) we tried to interview the users alone. However, in three cases it was necessary to include "significant others". Not letting people speak for themselves threatens the credibility of the study (Tøssebro, 1998). We do not know if the data from "significant others" correspond to the true attributes of what users desire of EAPs. To increase the credibility of the study, we could have limited the population to users who can speak for themselves. The purpose of this study is, however, to find attributes which are applicable and consistent for all users who have personal assistance according to the "Assistance Benefit Act" (the reasoning behind this is that we would not like to omit a group of people who are among the most vulnerable in our society). Excluding users who can not speak for themselves would therefore threaten the study's transformability (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), credibility also refers to how well categories cover data, which means that no relevant data should be excluded and no irrelevant data included in the categories. Larsson (1993) has a similar point of view and states that the result of a qualitative study must cover all descriptions of the phenomena of interest at the same time as the result must be well structured. A challenge for the research team was to structure the results from such a comprehensive quantity of data. The users in this study have different needs of personal assistance and even different perspectives on the concepts personal assistance and EAP (it is worthy of notice that one interview, user 11, is very poorly represented because the user did not know the meaning of an EAP). However, our ambition was to select users with different views and experiences in order to gain perspective regarding the breadth of desired attributes of EAPs.

Agreements about categories were largely good between the authors. If not, further analysis was performed until consensus was reached within the research team. The research team confirm that no data related to the purpose have been excluded from the interview texts due to lack of a suitable category. Dependability refers to the degree the data collection and the data analysis change during the research process (Lincoln & Guba, 1985). According to Graneheim and Lundman (2004), the dependability is threatened when the data are extensive and the collection extends over time. Our ambition has been to pose questions covering the same areas for all the users, and interact in all interviews as if it was the first interview rather than taking the acquired insight of desired attributes of EAP from previous interviews into account. To reduce the effects from previous interviews, we analysed the data after all the interviews had been conducted. Corroboration in the process of analysis, among three different investigators, increases the dependability and the credibility of the study (Lincoln & Guba, 1985).

Data collection is influenced by the knowledge level, experience, biases and perspectives of the researcher, as well as by the information the participants are willing or able to provide (Barbara, 1992). As regards users of personal assistance it is very difficult to reach what Krippendorff (1980) refers to as “speech community”, because it is hard for us to relate to personal assistance. In one interview it was extremely difficult to understand the perspective of the user. The last words come from this user: ”It is very windy today. I know a person, who has sailed on the seven seas. For him it is not windy at all.”

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Table 1

Categories of people qualified for personal assistance

Category 1	Users with "mental retardation" (Act 1993:387), with autism or with an autism-like condition.
Category 2	Users with a considerable and permanent intellectual functional impairment after brain injury in adult age. The impairment must have been caused by external force or physical illness.
Category 3	Users with some other lasting physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are major and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.

Note. The three heterogeneous categories are not motivated by scientific considerations, but reflect administrative/judicial ambitions.

Table 2

The categories, the sub-categories and their frequencies

1. Having a proper ideology of personal assistance: 7 (2, 6, 7, 8, 9, 10, 12)
   1. Following the legal framework of personal assistance: 4 (7, 8, 9, 10)
   2. Having the user's well-being as first priority: 2 (9, 12)
   3. Adapting the assistance to the specific user's needs of assistance: 5 (2, 6, 7, 8, 10)
2. Interacting with the user in a service-minded way: 12 (i.e. all users)
   4. Empowering the user: 6 (2, 3, 4, 7, 8, 9)
   5. Caring about the user: 8 (4, 5, 6, 7, 8, 10, 11, 12)
   6. Supporting the user when the user asks for a favour: 6 (2, 5, 6, 8, 9, 10)
   7. Reducing the user's workload related to personal assistants: 2 (10, 12)
   8. Providing assistants in all situations: 3 (1, 4, 5)
   9. Providing a limited number of assistants to the specific user:1 (8)
   10. Arranging training for users/legal guardians: 1 (10)
   11. Arranging social activities for users: 3 (5, 6, 10)
   12. Covering extra costs related to personal assistants: 2 (5, 10)
3. Mediating between users and personal assistants: 7 (2, 4, 5, 7, 8, 10, 12)
   13. Arranging meetings: 3 (7, 10, 12)
   14. Handling conflicts between the user and the assistants: 5 (2, 4, 5, 8, 12)
4. Providing good working conditions for personal assistants: 8 (1, 3, 6, 7, 8, 9, 10, 12)
   15. Arranging training for personal assistants: 4 (6, 7, 9, 10)
   16. Providing good administrative conditions of employment for assistants: 3 (3, 8, 12)
   17. Arranging supervision for personal assistants: 3 (7, 9, 10)
   18. Providing instrumental rules and instructions for personal assistants: 2 (1, 7)
5. Representing the user politically: 2 (6, 9)
   19. Being politically engaged on the behalf of the user: 2 (6, 9).

Note. The figure after each category refers to the number of users falling into this category and the figures within each parenthesis refer to the specific users.

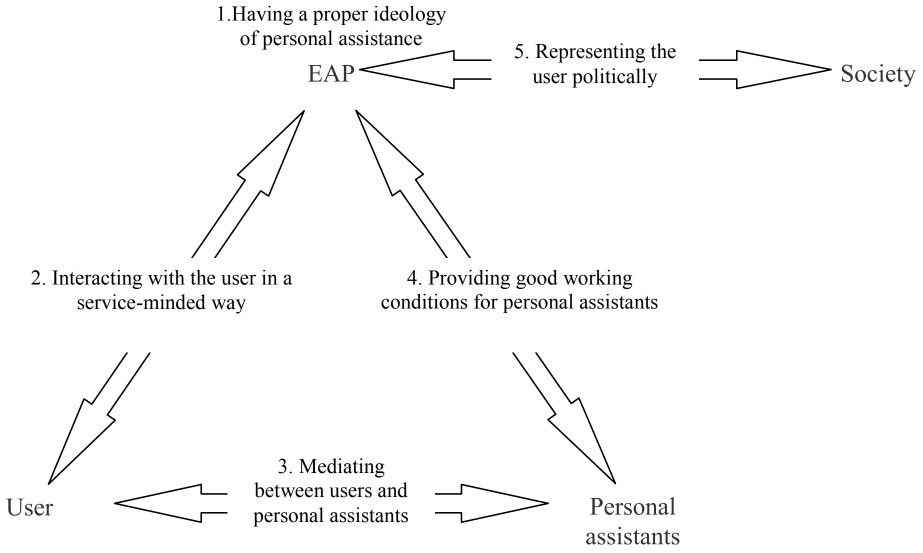

Figure 1. Matrix of actors and five categories of desired attributes of the EAP from the perspective of the user.

III

Running head: USER-SATISFACTION

Arranging Home-Based Personal Assistance Through Private or Public Service Providers: How Satisfied Are Consumers?

John Magnus Roos and Erland Hjelmquist

University of Gothenburg

Correspondence:

John Magnus Roos

Department of Psychology

University of Gothenburg

Box 500

SE – 40530 Göteborg.

Phone: (voice) +46 31 786 1641, (fax) +46 31 786 4628

E-mail: magnus.roos@psy.gu.se

Abstract

This study describes Swedish consumers of personal assistance that arrange their personal assistance through different kinds of service providers (e.g. public and private). The study compares consumer-satisfaction of service providers between public and private organisations. The questionnaire is based on users' perceptions of desired attributes of service providers and personal assistants. From surveying 422 adults that arrange their personal assistance through service providers, we found that Swedish users of personal assistance are more satisfied with private service providers than public service providers. However, type of service provider does not explain user-satisfaction with personal assistants. This variable is explained better through the relation to the personal assistants at the time of employing them (e.g. familiar or non-familiar personal assistants).

Personal assistance is a prototype of care-giving in the era of deinstitutionalization, when health and social care is shifting from institutional settings to the private setting of the person's home (Allen & Ciambrone, 2003). For people with disabilities, personal assistance implied a shift from social segregation to social participation (Kim & Ross, 2008). Swedish personal assistance refers to personally designed support for people with disabilities, including help with the activities of daily living (e.g. personal hygiene, meals, dressing and communication with others), housekeeping, activities in working life and leisure activities (Act 1993:387; Act 1993:389; Grönvik, 2007). Personal assistance is not exclusive for the Swedish welfare state. It also exists in Norway, Denmark, UK, Germany, Holland, Ireland, the USA, Australia and New Zealand. In Sweden, personal assistance is established as a legal right for users and is completely financed by the government (Act 1993:387; Act 1993:389). For simplicity, we can view the user as a customer who receives a cheque from the government for which he or she can buy the assistance he/she desires (Norén, 2000). Almost all users (>96%) delegate the employer's liability to a service provider (SOU 2005:100). There are three different kinds of service providers; municipality, cooperatives and private firms. There are no legal formalities concerning what should be included in the care agencies' work and there are no legal barriers to entering the market. Instead of providing obligations, the parliament encourages the agency to listen to the desires of their specific users and independently adapt their assistance. This implies that the quality standards among different agencies might be different and sometimes contradictory (Hugemark & Mannerfelt, 2003).

Our general hypothesis is that different traditions, objectives and legal conditions among public service providers (e.g. the municipality) and private service providers (e.g. private firms and user-cooperatives), may be important to the consumer's level of service satisfaction. As the popularity of private care agencies grows (Figure 1), our attention turns toward understanding more about the different types of organisations and especially their impact on the consumer service experience. The purpose of this article is to investigate if customer satisfaction differs among users who consult private service providers and public service providers, respectively.

[Insert Figure 1 about here]

Little research has been done regarding how Swedish users of personal assistance assess their services. When personal assistance was established as a legal right in Sweden, some researchers (e.g. Gough, 1994; Hugemark & Wahlström, 2002) investigated the implications for the users having personal assistance instead of the previous support, home care. Research has also been conducted in order to evaluate the public goals of personal assistance (e.g. National Board of Health and Welfare, 2005; RiR 2004:7; SOU 2005:100).

Services related to people with disabilities often focus on what experts believe people with disabilities desire. To better design services, researchers must also investigate how consumers evaluate the service they receive (Gough, 1994; Söder, 1995; Lutz & Bowers, 2005). The present study describes and measures consumer satisfaction through quality attributes which are formulated by people with severe disabilities, the people personal assistance concerns.

Background

This study compares consumers receiving self-directed personal assistance from private service providers and public service providers respectively. All service providers are formal employers of their assistants. They are responsible for working conditions, according to Swedish law, varying from working environment to sick leaves. In general they also manage financial administration and recruitment of their personal assistants (Norén, 2000). Why then, would user satisfaction be dependent on what service provider is used? Each organization (public or private) is complex, with many conflicting norms and motives. Despite this, we have found three explanations, not necessarily independent from each other, for why user satisfaction with personal assistance might be different for private and public service providers. First, the organizations themselves have different raisons d'être. The fundamental objective of public health-care organizations is to achieve the best possible service within a limited budget (Le Grand, 2003)). All public services come under the same overall governmental budget, which implies that a surplus from one public service might be shared out to other public services. The overall objective is to allocate the budget in such a way that it will equalise the marginal health gain for each citizen (Le Grand, 2003). Objectives of private firms and user-cooperatives are more focused on the organizations' own activity and utility maximization for people in the organization. The fundamental objective of a private firm is to maximize, or at least to increase significantly, its market value for owners and for other parties who have an interest in the firm (Pinches, 1995). The fundamental objective of a user-cooperative is to provide good assistance to the members (users) of the cooperative (Jacobsson, 2007). Second, the organizations have different traditions. The municipality has been criticized for running personal assistance in the same manner as home self services (Hugemark & Wahlström, 2002). Home self service is regulated in the Social Service Act and is primarily given to elderly people and people with physical disabilities (Act 2001:453), while personal assistance is regulated in the Assistance Benefit Act and is given to people with all kinds of impairments (Act 1993:389). Characteristics of home self service are top-down organisations and standardised user support, while the ambitions of personal assistance are user influence and personally designed support (Hugemark & Wahlström, 2002). For the municipality, personal assistance is about providing personal assistants who can execute different kinds of tasks for the user. Cooperatives and private firms on the other hand, prefer to delegate as many tasks as possible to the users. For example decisions on salary and education for personal assistants are centralised for the municipality while such decisions are usually delegated to the specific user in the case of a cooperative or a private firm (Norén, 2000). Third, the organizations have different legal frameworks. The municipality has a legal responsibility towards users of personal assistance. According to the *Instrument of Government*, “it shall be incumbent upon the public institutions to secure the right to health … and to promote social care and social security” (Act 1974:152 § 2). This implies that the municipality must provide assistance to users who do not choose assistance provider themselves and to users who are, for one reason or another, omitted by other assistance providers. The representatives of the municipality, as public officials, must follow Swedish legislation in the public sector; *"*public power shall be exercised under the law*"* (Act 1974:152 § 1). Representatives of private firms and cooperatives are freer to run personal assistance in their own interest.

According to Le Grand (2003), private health care organisations have an interest in finding healthy patients who are undemanding and need little care. Because different service providers of personal assistance have different legal frames and raisons d'être, there is a possibility that pro-profit organizations "cream skim" the market while the municipality have to take care of the more demanding clients.

This study has been designed to address two questions: (a) Are there differences in the characteristics of consumers who receive their assistance from the municipality compared with those who consume their assistance from private firms and cooperatives? (b) Does consumer satisfaction with home-based personal assistance differ between public and private service providers?

Method

Participants

The present study was carried out in the City of Gothenburg. Gothenburg is appropriate for a comparative study since the different service providers are all active and well represented there. (SOU 2005:100). Criteria for inclusion of persons in the study were: resident in the City of Gothenburg; at least 18 years of age and personal assistance for basic needs (e.g. personal hygiene, eating, dressing and communication) for more than 20 hours a week. All users in the City of Gothenburg who met the inclusion criteria and whose addresses were available at the Swedish Social Insurance Agency (N = 440) received a questionnaire in Swedish, a postage-free return envelope, and a cover letter explaining the study. To increase the response rate, a reminder was sent 3 weeks later. Both letters also included information to the users' administrator, in cases when the users were not able to give consent to participation themselves. Instead of omitting users with severe disabilities, we asked "significant" others (e.g. parents and social workers) to answer the questionnaire (Tøssebro, 1998). The population-frame also included users who arranged their personal assistance themselves. We do not know how many users in Gothenburg arrange their personal assistance themselves instead of using a service provider. The proportion of Swedish users who do not have a service provider is approximately 4 percents (SOU 205:100). We assume that the proportion in Gothenburg is the same as in the rest of Sweden, which gives us an estimated population of 422 users (N = 422). A total of 179 users returned the questionnaire. We excluded questionnaires from users who arranged their personal assistance themselves (n = 11), which implies that 168 users (of 422) have been included in this study (estimated response rate = 39.8%).

The questionnaires were distributed by the Swedish Social Insurance Agency and the research team did not have access to the mailing list. Users' addresses are protected and were only available at the Swedish Social Insurance Agency. Before the user (or the administrator) consented to participate (by answering the questionnaire), all contact between the researchers and the user was mediated by the Swedish Social Insurance Agency. The study is in accordance with the

Swedish law on research ethics and approved by the regional ethical review board in Gothenburg (GO 082-08).

Instrument

The questionnaire covered areas such as demographic data (e.g. age, gender, citizenship), hours per week of personal assistance, number of years using personal assistance, number of years with the current service provider, type of disability (e.g. physical disability and/or mental disability/intellectual disability), relations to personal assistants at the time of employing them (e.g. familiar assistants, family member or friend, or non-familiar assistant), and attitudes to service providers and personal assistants. The questionnaire also included a question about user involvement in the study (e.g. if the answers measure the users own perceptions or if the user has been influenced/represented by a "significant" other). In this study, attitude measurements are used to determine customer-satisfaction between different actors on a market (Kinnear & Taylor, 1996). To increase the reliability, we measured attitudes to service providers in three different ways:

(1) Direct attitude to the service provider. The question read: "How good is your service provider?" The response format was a 5-point Likert scale, ranging from very bad (1) to very good (2).

(2) A multiattribute attitude model (Fishbein & Ajzen, 1975) based on attributes related directly to the service provider. According to the model, a person's attitude toward any object is a function of her/his beliefs about the object and the

implicit evaluative responses associated with those beliefs. Using this approach, an attitude toward a particular service provider can be represented as:

$$A_{SP} = \sum_{i=1}^{n} b_i e_i$$

Where A_{sp} is the attitude toward the Service provider (SP); b_i is the *belief* (Fishbein & Ajzen, 1975) i about SP, i.e. the subjective probability that SP is related to attribute i; e_i is the evaluation of attribute i; and n is the number of attributes. This variable is the sum of the products of two subscales, beliefs about service providers and belief evaluation (Fishbein & Ajzen, 1975). The particular attributes were generated from a qualitative study of users' desires of service providers (Roos, 2009) and include: 1) having a proper ideology of personal assistance, 2) interacting with the user in a service-minded way, 3) providing good working conditions for personal assistants, 4) mediating between users and personal assistants, 5) representing the user politically. For each attribute, the question read: "Indicate how well you think the statement is applicable to your service provider". "I think my service provider (attribute)?". A 7-point Likert scale was used, ranging from "completely disagree" (-3) to "completely agree" (+3). The belief evaluation items referred to the importance of each attribute, and were measured by a 7-point bipolar Likert scale, varying from "extremely unimportant" (-3) to "extremely important" (+3). In Likert scaling, disagreement with an item is assumed to be indicative of the person's attitude. Thus disagreement with a negative statement is taken as an indication of a positive attitude (Fishbein & Ajzen, 1975). This implies that the total scale for variable 2 is -45 to +45.

(3) A multiattribute attitude model based on the service provider's personal assistants. This variable is the sum of the products of the two subscales, beliefs about the service providers' personal assistants and belief evaluation (Fishbein & Ajzen, 1975). The specific attributes were generated from a qualitative study of users' desires of personal assistants (Roos, 2009) and included the following attributes: 1) discreet, 2) obedient, 3) reliable, 4) informative, 5) alert, 6) respectful, 7) considerate, 8) friendly, 9) pleased and 10) practical. The item read: "I think my personal assistants are (attribute)?" and were measured on a 7-point Likert scale, varying from "completely disagree" (-3) to "completely agree" (+3). The belief evaluation items asked about the importance of each attribute, and were measured on a 7-point bipolar Likert scale, ranging from "extremely unimportant" (-3) to "extremely important" (+3) (Fishbein & Ajzen, 1975). This implies that variable 3 varying from -90 to + 90.

Data analysis

The first question (e.g. *Are there differences in the characteristics of users who receive their assistance from the municipality compared with those who receive their assistance from private firms and cooperatives?*) has been analyzed using chi-square analyses for categorical data (e.g. gender, type of disability and relation to personal assistants at the time of employing them) and paired sample T-tests for continuous data (e.g. age, hours per week of personal assistance, years using personal assistance, years with current service provider). A p-value of less than 0.05, in comparing user characteristic between public and private service providers, was used as the statistical significance level.

The second question (e.g. *Does consumer satisfaction with home-based personal assistance differ between public and private service providers?*) has been analyzed with Mann-Whitney tests. (The test variables were not normally-distributed and log transformations did not correct the problem. Therefore we have used a test that does not rely on the assumption of normally-distributed data). The test variables have been (1) direct attitude to service providers, (2) sum of desired attitudes related to service providers, and (3) sum of desired attitudes related to service providers' personal assistants. The grouping variable in each of the three tests was type of service provider (e.g. public or private). For all analyses, we used the SPSS statistical software package.

Results

Consumer characteristics and type of service provider

There were almost no statistically significant ($p<.05$) differences between users who arrange their personal assistance through public service providers and users who arrange their personal assistance through private service providers. However, users who arrange their personal assistance through private service providers have had their service provider two years shorter on average. It is also worth pointing out that users who have public service providers were more often represented by "significant others" than users who have private service providers.

[Insert Table 1 about here]

Consumer satisfaction and type of service provider

Two of the three variables for measuring user-satisfaction indicated that there are significant differences ($p < .05$) between the two groups (Table 2). Users who have private service providers seem to be more satisfied with their service provider than users who have public service providers.

[Insert Table 2 about here]

On the direct question about user-satisfaction (variable 1), users with private service providers reported that they were more satisfied than users with public service providers (Table 2). Figure 2 illustrates how consumer satisfaction is distributed between public and private service providers. The median value for both groups was 4, which indicates that users in general were satisfied with their EAPs.

[Insert Figure 2 about here]

Also on attitudes to service providers measured through the multi-attribute model, user-satisfaction with private service providers was significant ($p < .05$) higher than user-satisfaction with public service providers (Table 2). The median value for users with private providers was 33.5 and the median value for users with public providers was 28.5. Concerning attitudes toward the service providers' personal assistants, there were no significant ($p < .05$) differences between users with private service providers and users with public service providers (Table 2). The median value for users with private providers was 50.0 and the median value for users with public providers was 59.5.

Discussion

Methodological considerations

Our approach has been to let people with severe disabilities speak for themselves and the users of personal assistance have been our first choice of respondents. However, the situation causes problems when it comes to people with intellectual disabilities who are not able to participate in such a study, where linguistic communication is an essential ingredient. One option would have been to exclude users who could not answer the questionnaire. We did not consider this to be a good choice, because it means omitting a group of people who are among the most vulnerable in our society. The most common alternative to subjects speaking for themselves, is to ask "significant" others to respond (Tøssebro, 1998). This was our choice as well. When asking others, another component is introduced through this other person, for instance a legal administrative, a family member or a personal assistant. According to Tøssebro (1998) there may be some discrepancies between what significant others answer and what users really perceive. He states, however, that this type of bias should not be over-estimated and that staff and family members in general are able to respond reliably on a wide range of questions concerning living conditions of people with intellectual disabilities (Tøssebro, 1998). Our assumption when we designed the study was that such a potential bias would have a similar impact on both groups, so that group differences still would be valid.

According to Nanna and Sawilowsky (1998), the nature of Likert scales creates non-normal distributions and ceiling or floor effects. Classical parametric statistics (for instance regression analyses) have underlying assumptions about normally distributed test variables (Altman, 1991). The three test variables in the present study were characterised by significant ($p<.01$) negative skewness and kurtosis (e.g. pointy distribution) and log transformations did not correct the problem. In order to not violate the assumption of normality, we used nonparametric statistics (Siegel & Castellan, 1988).

Discussion of the findings

The purpose of this study was to investigate if customer satisfaction differs among users who arrange personal assistance using private or public service providers. This study indicates that there are differences in customer-satisfaction among the two service providers. Users of personal assistance are more satisfied with private service providers than public service providers. Such a finding is very important because it can help people with severe disabilities to improve their every day life through making an informed choice – a change of service provider. This finding also raises new questions such as; how can public service providers be better?

As discussed in the introduction, we thought that different goals of the organisations and different legal frame-works should have influenced the characteristics of the users. According to previous studies (e.g. SOU 2005:100), we know that some private service providers only provide assistance to people with physical disabilities. We also know that the municipality must provide assistance to users who are omitted by other assistance providers. Therefore, we were somewhat surprised that the two groups did not significantly differ in respect to type of disability (Table 1). There are, however, at least two indications that there are some differences between types of disability across the two groups. First, users with public service providers in the present study have significantly more often being represented or influenced by "significant" others (Table 1). This might imply that users with public service providers are people with more severe disabilities than users with private service providers. Second, we had almost a significant ($p<.05$) difference in the proportion of people with intellectual disabilities between the two groups (Table 1). Our statistical methods have prevented us from determining how much the variable *type of service provider* contributed to variation in user-satisfaction, while holding constant the effect of other variables (e.g. type of disability). The question is if type of disability is a confounder (MacKinnon, Krull, & Lockwood, 2000) which falsely accentuates a relationship between type of service provider and user-satisfaction. Two Mann-Whitney tests (one for variable 1 and one for variable 2) have been carried out in order to investigate if there is a significant ($p<.05$) difference in user-satisfaction between users with a physical disability only and users with an intellectual disability. The tests showed that there was no significant difference in user-satisfaction between users with a physical disability only and users with an intellectual disability. Therefore, we can reject the hypotheses that type of disability works as a confounder between our test and grouping variables.

Answers from users with public service providers are significantly more often influenced/represented by "significant" others, than answers from users with private service providers (Table 1). How do we know if the differences in user-satisfaction of service providers between public and private users are caused by different objectives and legal conditions between public and private service providers, or simply by a methodological bias related to inclusion of "significant" others? If bias exists between "significant" others and true user attitudes, the bias will be larger in the group of users with public service providers (Table 1). According to previous research, this might however not explain differences in user-satisfaction. If a bias exists, it would rather have a positive impact on the users' true attitudes, because some significant others are social workers who defend the service they are providing (Tøssebro, 1998). Fortunately, the design of our study allowed some clarifications of this issue. We tested the existence of a bias through two Mann-Whitney tests, one for variable 1 and one for variable 2. According to both tests, users who have formed their perceptions themselves did not significantly ($p<.05$) differ in user-satisfaction from users who have been influenced or represented by "significant" others.

Table 1 also shows that there is a significant difference between the two groups concerning length of time with the service provider. Users with public service providers have had their providers two years longer on average. This is reasonable, because the municipality must provide assistance to users who do not choose assistance provider themselves. In the beginning of the reform, private service providers were not very common and most people had the municipality as their service provider. In the present study, the majority (51%) of the users with public service providers have had their service providers ten years or longer, while less than a quarter (23%) of the users with private service providers have had their service providers ten years or longer.

This study indicates that user-satisfaction with personal assistants might not be significantly influenced by the type of service provider. Previous research (e.g. Ruth & Benjamin, 2008) shows that user-satisfaction with personal assistants depends on the relation to personal assistants at the time of employing them. Users who arrange their personal assistants through family members and friends are more satisfied than users who arrange their personal assistants through other, non-familiar persons (Ruth & Benjamin, 2008). A Mann-Whitney test was carried out to investigate if there is a significant difference in user-satisfaction with personal assistants between employing friends or family members and employing others. The test variable was variable 3 (e.g. sum of desired attitudes related to service provider's personal assistants) and the grouping variable were relation to personal assistant at the time of employing them (e.g. group one; family members and friends and group two; non-familiar persons). The test confirmed previous research and states that Swedish users are also more satisfied with their personal assistants when they employ friends and family members than when they employ non-familiar persons. According to Table 1, users with public providers employ friends and family members as personal assistants more often than users with private providers, which might explain the higher median value in user-satisfaction of personal assistants for this group.

Finally, the overall positive attitude to service providers and personal assistants among users of personal assistance should be commented. The finding that users are more satisfied with private service providers than public service provider does not mean that users are dissatisfied with public service providers. The median value of satisfaction for users with public service providers is 4 on a scale varying from 1 to 5, where 5 is the highest score. The median value of user-satisfaction for users with public service providers is 28.5 on a scale varying from -45 to +45. Why are Swedish users of personal assistance very positive to their service providers and personal assistants? It might simply be that the Swedish assistance reform has been very successful and that people with severe disabilities are very satisfied with the arrangements of Swedish personal assistance. However, it is possible that users of personal assistance respond that they are more satisfied than they really are. According to Wilde, Larsson, Larsson and Starrin (1995), such responses are especially common in survey studies targeting vulnerable groups of people (e.g. elderly people and uneducated people). This might be explained through cognitive dissonance; a feeling of psychological tension or doubt the person experiences after understanding that he/she can not change her/his situation in the way he/she would like to. This dissonance can be reduced through reappraising the current situation, or reducing the requirements of the service or support (Wilde, Larsson, Larsson and Starrin, 1995). The reappraisal strategy has for instance been identified among users of elderly care; they are grateful and happy for being “cared” for and do not want to complain (Möller, 1996). This strategy has also been identified among individual in a stage where death is approaching. Some people with cancer reappraise their situations in order to live as good as possible (Winterling et al., 2006).The reduced requirement strategy has been identified for patients in psychiatric care and implies that users reduce their expectations and adjust themselves to satisfaction on a lower level (Henderson, 2004; Davies, 2005). In both cases, the respondents report satisfaction values with the service/support that are too high (Wilde, Larsson, Larsson & Starrin, 1995).

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Table 1

User characteristics by type of service provider

	Public (n = 59)	Private (n = 109)	Public vs. Private (*p*)
Age			
M	50.6	46.9	0.13
SD	15.4	14.6	
Gender (% female)	44.8	48.1	0.68
Ethnicity (% Swedish)	88.9	91.6	0.58
Type of impairment (% physical, only)	53.4	68.5	0.06
Type of personal assistants (% family or friends)	35.8	24.0	0.12
Assistance hours per week			
M	104.8	122.0	0.06
SD	56	52	
Years with personal assistance			
M	9.4	10.4	0.14
SD	4.2	3.9	
Years with service provider			
M	8.4	6.4	0.01
SD	4.5	4.6	
User involvement in the study (% users' own perceptions)	52.6	75.2	0.00

Table 2

Consumer satisfaction of service providers and personal assistants, by type of service provider

	Municipality (n = 55 - 56)	Private (n = 103 - 108)	Municipality vs. Private (*p*)
Variable 1			
Direct attitude to the service provider			
Average rank	69.2 (n = 55)	85.0 (n = 103)	0.03
Variable 2			
Attitude model based on attributes of the service provider			
Average rank	70.8 (n = 56)	87.8 (n = 107)	0.03
Variable 3			
Attitude model based on attributes of the service provider's personal assistants			
Average rank	89.3 (n = 56)	79.0 (n = 108)	0.19

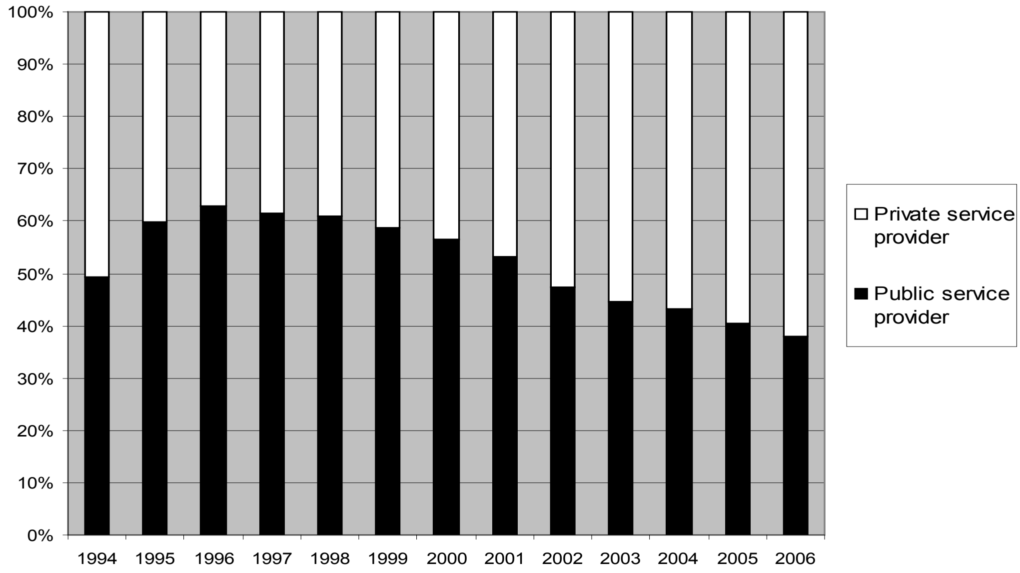

Figure 1. Market shares across private and public service providers during the period 1994 – 2006 in the city of Gothenburg, (based on data from the Swedish Social Insurance Agency).

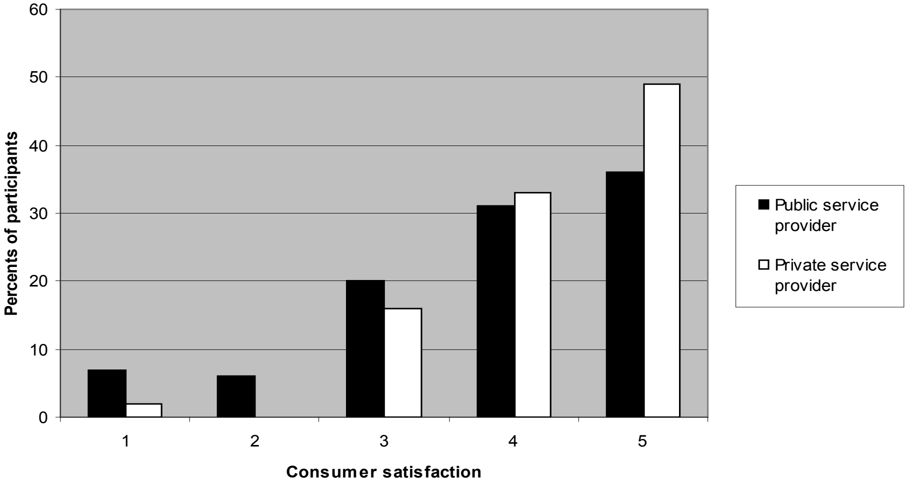

Figure 2. Consumer satisfaction across service providers.

IV

Running head: NUMBER OF ASSISTANCE HOURS

Swedish personal assistance; provided according to needs or according to service provider?

John Magnus Roos[1], Erland Hjelmquist[1] and Katarina Steen-Carlsson[2]

University of Gothenburg[1]

Lund University[2]

Correspondence:

John Magnus Roos

Department of Psychology

University of Gothenburg

Box 500

SE – 40530 Göteborg.

Phone: (voice) +46 31 786 1641, (fax) +46 31 786 4628

E-mail: magnus.roos@psy.gu.se

Abstract

Swedish personal assistance for people with severe disabilities became a legal right in 1994. The support is completely financed by the government and with a few exceptions transferred to the users' service provider. There are three types of service providers; the municipal providers, private firms and user-cooperatives. The purpose of the present study was to investigate if users with user-cooperatives and private firms respectively, have received more assistance hours than users with municipal providers. The study was based on a panel of 4564 observations on 657 users of personal assistance. The results show that users with private providers received 18.4 percent more assistance hours compared to users with municipal providers during the period 1994-2006. The difference between private firms and municipal providers could not be explained by user specific variance. Taking user specific variance into account, there was no significant ($p<.05$) difference of number of assistance hours between users with user-cooperatives and users with municipal providers. The findings are discussed in relation to the judicial decision process regarding assistance hours, incitements for different service providers and the specific circumstances of the Swedish assistance market.

Introduction

Over the last twenty years a great number of public-sector reforms in several OECD countries have taken place. The most far reaching reform is privatization (Brunsson & Sahlin-Andersson, 2000). Private actors are seen as more efficient in allocating resources than public actors and the privatization of social services is intended to improve public services by introducing competition and choice (Savas, 2002). A less radical reform than privatization is the use of vouchers. A voucher is an earmarked grant from the government to the welfare recipient. Vouchers are often associated with the advantages of privatization but also entail the suppliers' facing significant government regulation of the earmarked commodities provided or their operations more generally (National Bureau of Economic Research, 1999).

Swedish personal assistance is based on a voucher system, in which the government provides a specified amount of money for each recipient (e.g. user/ person with disability) to spend on personal assistance. The amount is directly based on number of assistance hours and the cost for one hour is the same for all Swedish users. The number of assistance hours is solely based on the user's personal need of assistance and not on diagnosis or impairment. According to the law (i.e. "The Assistance Benefit Act (1993:389)"), the user has the right to the voucher. Almost all users (approximately 97%) of personal assistance in Sweden purchase their assistance from a service provider, of which there are three different types, public organisations (e.g. the municipality), user-cooperatives and private firms (Norén, 2000). In practice, a user who arranges personal assistance through a service provider also informs the Swedish Social Insurance Agency to transfer her/his money to the provider. The transferred money should cover salaries for personal assistants and other expenses related to personal assistance (e.g. administrative costs and educational costs). If the provider is able to keep the costs of a specific user lower than the voucher, the surplus can be used for other users and/or as profit for the owner(s). A service provider has no judicial obligations to declare what the money is used for and the government has no efficient routines to follow-up what the money is used for (RiR, 2004:7).

The personal assistance market in Sweden is interesting in that it allows different types of organisations to compete for the same customers. However, different organisations have different objectives and face different legal regulations, which might have influenced their possibility and incentive to influence the number of assistance hours for their users. The overall purpose of the present study is to investigate if type of service provider is associated with the number of assistance hours the user receives.

Personal assistance in Sweden

Two acts that regulate Swedish personal assistance came into force in 1994: “Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments” and “The Assistance Benefit Act (1993:389)”. Personal assistance was then established as an individual right for users who qualified for the service (SOU 2005:100). According to the Act (1993:387), users qualifying for personal assistance comprise three different categories of people:

- Category 1: Users with mental impairments, with autism or with an autism-like condition.
- Category 2: Users with a considerable and permanent intellectual functional impairment after brain injury at adult age. This only applies to impairment(s) caused by external force or physical illness.
- Category 3: Users with some other lasting physical or mental functional impairment which is manifestly not due to normal ageing, if this impairment is major and causes considerable difficulties in daily life and, consequently, an extensive need for support and service.

According to Swedish law, personal assistance refers to personally designed support that is provided by a limited number of persons (personal assistants) for persons (users) who, owing to major and lasting functional impairments, need assistance with their basic needs (Act 1993:387). Basic needs are defined as; ”personal hygiene, meals, dressing and undressing, communication with others or other help that requires extensive knowledge about the person with a functional impairment” (Act 1993:387, §9a). If a person needs personal assistance for her/his basic needs he/she can also receive personal assistance for other personal needs if those needs are not satisfied in another way. Those “other personal needs” are not clearly defined in the act and the government has proposed that this should be made clear and explicit in order to gain control of the cost of personal assistance (Swedish government bill 1995/96:146). During the period 1994 – 2007, the costs of people with personal assistance according to the Assistance Benefit Act (1993:389), have increased from about 4 billion SEK to more than 18 billion SEK (SOU 2008:77). Personal assistance should promote equality in living conditions and full participation in society. The aim of personal assistance is to give users the possibility "to live as others do" (Act 1993: 387, §5; Act 1993: 389).

The "law of rights" implies that the decision process, concerning for example entitlement to personal assistance and number of assistance hours, always starts with a formal application from the person with a disability, see Figure 1 (Åström, 1998; Barron, Michailakis & Söder, 2000). If the user is unsatisfied with the decision by the Swedish Social Insurance Agency, he/she can appeal to an administrative court (RiR, 2004:7).

[Insert Figure 1 about here]

Users who receive personal assistance must not live in group housing or be cared for at an institution (Swedish Social Insurance Agency, 2007). There is no lower age restriction for when personal assistance can be provided and since 2001, there is no upper age limit. (Norström & Thunved, 2008). However, to be granted assistance after the age of 65, the person must have already received assistance before the age of 65. The number of hours can not be increased after the age of 65 (Act 1993:387).

The local community council is financially responsible for users who need personal assistance for less than 20 hours a week. If a person needs personal assistance for their basic needs for more than 20 hours a week, he/she may be entitled to assistance benefits. Besides assistance for basic needs, the assistance benefit should support the user with a wide range of services in areas such as working life, leisure activities, cleaning and other areas (Grönvik, 2007). The right to this benefit is regulated in the “Assistance Benefit Act (1993:389)”. The Swedish Social Insurance Agency takes the decision on all issues related to assistance benefits. The local community council is financially liable for the first 20 hours of personal assistance in such cases too (Swedish Social Insurance Agency, 2007).

Three types of service providers

Despite the fact that the municipality (i.e. local council) and the Swedish Social Insurance Agency are financially liable for the users’ personal assistance, the users are free to choose which service provider to consult for practical provision of personal assistance. In 2005, 59% of the Swedish users arranged assistance through municipality providers (i.e. public organisations). The market shares for private firms and user-cooperatives were 26% and 12% respectively. About 3% of the Swedish users of personal assistance were own-managers (SOU 2005:100).

Characteristics of public organisations in general are political democracy, public ethics and security of life and property (Skålén, 2004). Public organisations in Sweden are characterised by democratic values, such as equal treatment and participation for all citizens in society (Jacobsen & Thorsvik, 2008). The fundamental objective of public health-care organizations is to achieve the best possible service within a limited budget (Le Grand, 2003). Public organisations differ from private organisations in their legal framework (Boston, Martin, Pallot & Walsh, 1996). According to the Swedish law (Act 1974:152), public organisations must provide assistance to users who do not choose an agency themselves and to users who are, for one reason or another, omitted by other agencies. Representatives of public organizations, in their capacity as public officials, must exercise the public power under the law (Act, 1974:152). Private firms and user-cooperatives are freer to run personal assistance in their own self-interest. The fundamental objective of a private firm is to maximize the market value of the firm (Pinches, 1995). The fundamental objective of a user-cooperative is to provide good assistance to the members (users) of the cooperative (Jacobsson, 2007).

Research questions and hypothesis

As described above, different service providers have different legal frameworks and different objectives. Compared to municipal service providers, it seems that private firms and user-cooperatives have more incitements and more possibilities to increase the number of their users' assistance hours. Our hypothesis is that users with private firms and user-cooperatives have received more assistance hours compared to users with municipal providers. The present study has been designed to address two questions:

- Do users with private firms as providers receive more assistance hours than users with municipal providers?

- Do users with user-cooperative providers receive more assistance hours than those with municipal providers?

Method

Design and participants

The present study is based on a longitudinal research design including 4564 observations on 657 users of personal assistance, during the period 1994 – 2006. Inclusion criteria were: (1) at least 18 years of age, (2) at least 20 hours of personal assistance per week (i.e. assistance according to the "Assistance Benefit Act (1993:389)", and (3) resident in the municipality of Gothenburg., Participants had to meet all three criteria simultaneously for at least one year (on the 15th of November) during the period 1994- 2006. Gothenburg is the second largest city in Sweden with a population of almost half a million (City of Göteborg, 2008). Gothenburg was appropriate for a comparative study since the different service providers were all active and well represented there. (SOU 2005:100). Data about gender, nationality ("Swedish" or "other than Swedish"), type of service provider, type of impairment and number of assistance hours were retrospectively derived from central and local registries at the Swedish Social Insurance Agency. The study was approved by the regional ethical review board in Lund (dnr 563/2006).

Study variables

The dependent variable was number of assistance hours per week the 15th of November every year. Independent variables have been gender, nationality

("Swedish" or "other than Swedish"), age, years using personal assistance, type of impairment, and type of service provider. Type of impairment has been classified through:

(1) Type of impairment as defined by Swedish law (Act, 1993:387); category 1, category 2 and category 3, as previously described.

(2) Type of impairment (or disease) as defined by "The tenth revision of the International Statistical Classification of Diseases and Related Health Problems", "ICD-10", (World Health Organisation, 2008). Our population has been divided into six categories. The first category consisted of people with mental and behavioural disorders, whatever reason for the disorder. The second category consisted of people with disabilities caused by external forces. The category excluded people who acquired a mental or behavioural disorder as a consequence of external causes. The category also excluded birth trauma and obstetric trauma. The third category consisted of people with diseases of the nervous system. The fourth category consisted of people with diseases of the musculoskeletal system and connective tissues. Both category 3 and 4 excluded people with diseases caused by external forces and people who, beside the diseases, also had mental and behavioural disorders. In cases when health problems were caused by diseases in both the nervous system and the musculoskeletal system and connective tissues (n = 15), the category which is mentioned first in the documents of the Swedish Social Insurance Agency was chosen. According to administrative staff this was an indication of the most salient disease (R. Jönsson, personal communication, February 7, 2007). . The fifth category consisted of

people with diseases and related health problems classified by the ICD-10 as other diseases and health problems than those in our four main categories. The sixth category consisted of people with undefined health problems.

Statistical analysis

The first step was to give descriptive and graphic analyses of number of assistance hours across different service providers during the period 1994 – 2006.

The second step was to investigate if observed differences in number of assistance hours between the three types of service providers were significant when we controlled for other independent variables. Panel data regression methods were used as the assumption of independence between observations of the standard ordinary least squares method was violated since we had longitudinal data on the number of hours granted per week each year for each user. We present the estimated equations by random effects for the standard model (Jones, Rice, Bago d'Uva & Balia, 2007; StataCorp, 2007). The random effects models treats the individual specific effects as randomly distributed across individuals and parameters are estimated for time-varying and time invariant variables. The analyses controlled for the effects of gender, age, nationality, type of impairment and years with personal assistance. For most users (n = 599) we also had more than one observation, which allowed us to control for user-specific variance, which are not included in other independent variables. The present study considered a p-value of 0.05 as statistically significant. All statistical analyses were performed using Stata v10.0 (StataCorp, 2007).

The dependent variable (i.e. hours of assistance per week) was skewed to the left. Therefore, we used the logarithmic transformation in the regression analyses. Coefficients from logarithmic models are interpreted as a percentage effect of an independent variable upon a dependent variable.

Sensitive analyses

Our panel data regression includes several qualitative variables with more than two categories. For each category, we created a dummy variable which we defined as a reference group (e.g. 18 – 29 years of age, impairment category 1 according to the Act (1993:89), impairment category of mental and behavioural disorders according to the ICD-10). The coefficients (*B*) of the dummy variables represent expected differences in assistance hours relative to the reference group. This implies that the effect from a specific category may change if the reference group is changed. The critical question for the present study was if such a category change of an independent variable would change the relation between type of service provider and number of assistance hours. In order to explore this, we have changed reference group in the age variable from “18 – 29” to ”40 – 49”, the ICD-10 variable of “type of impairment” from mental and behavioural disorders to “diseases of the nervous system”, and the “type of impairment” category according to the Act (1993:89) from “category 1” to “category 3”, respectively. Further, we also made the three changes simultaneously. Irrespective of reference group, the effect of type of service provider on the number of assistance hours remained constant.

Results

The median values in assistance hours between the three different service providers are illustrated in Figure 2. The figure show that users who have had municipal providers have had less assistance hours during the period 1994 – 2006 compared to users who have arranged their personal assistance through private firms or user-cooperatives.

[Insert Figure 2 about here]

Figure 2 do not tell us anything about other variables than type of service provider, which may influence the number of assistance hours. Therefore, Figure 2 has been supplemented with an analysis in which we have controlled for the effect of demographic factors, type of impairment, years using personal assistance (Table 1) and other individual-specific variance. The estimated coefficient (B) is the marginal effect on number of assistance hours of having a specific value on a variable during the period 1994 – 2006. Table 1 shows that an average user with a private service provider has received 18.4 percent ($p<.05$) more hours than a user with the municipality as their service provider during the period 1994 – 2006 (Table 1). During the period 1994-2006, there was no significant effect ($p<.05$) on the number of assistance hours between an average user with a user-cooperative as their service provider and an average user with a municipal service provider, when we controlled for the effects of demographic factors, type of disability and years using personal assistance (Table 1). The trend variable (years using personal assistance) implies that number of assistance hours for an average user increases by 3 percent per year using personal assistance, which also correspond to Figure 2.

[Insert Table 1 about here]

Discussion

The longitudinal design and large sample size of this study are strengths in determining the “pure” effect (Hill, Griffiths & Judge, 2001) of type of service provider on the number of assistance hours. The design allows us to control for individual specific variance, which might not be captured by cross-sectional designs. Our panel data regression also allowed us to control for effects above and beyond the effects of demographic variables, type of impairment, and number of years using personal assistance.

The present study indicates that number of assistance hours for a person with a severe disability is not only based on his/her unique needs for personal assistance, but also on the incitements of his/her service provider. During the period 1994 – 2006, users who arranged their personal assistance through private firms received 18.4 percent more assistance hours per year compared to users who arranged their assistance through the municipality. This was the effect of having a private service provider, compared to a municipal provider, above and beyond the effects of individual specific variance that we controlled for. Such findings are reasonable considering the fundamental objective of a private firm (i.e. profit maximizing), in combination with several particularities of the Swedish assistance market:

- During the period 1994 – 2006, the Swedish Social Insurance Agency distributed about 119 billion SEK for users with personal assistance according to “The Assistance Benefit Act (1993:389)” (SOU 2008:77).
- There are no barriers to entering the market of Swedish personal assistance (Norén, 2000).
- There are no clear specifications of what type of costs assistance money should cover. (SOU 2005:100; Swedish government bill 1995/96:146; RiR, 2004:7).
- There are no efficient controls over what the assistance money is used for (SOU 2005:100: RiR, 2004:7).

All the circumstances above indicate why personal assistance is a profitable market. However, the conditions do not say anything about how a private firm can influence the number of assistance hours. This issue is critical for the reliability and validity of the present study, since if a private firm does not have the possibility to influence the decision process, type of service provider can not explain differences in number of assistance hours.

The judicial decision process concerning number of assistance hours (Figure 1) includes several unspecified and unclear concepts, which prevent objective decisions by the Swedish Social Insurance Agency and by the higher court organization (RiR, 2004:7). Decision- makers at the Swedish Social Insurance

Agency consider the concept "need" as vague and impossible to judge on objective criteria (RiR, 2004:7). One decision-maker stated that "imagination and experience" are necessary ingredients in the decision process (RiR, 2004:7, p. 37). According to Åström (1998), there is no objective definition of the concept "good living conditions", which implies that the decision makers always have to make subjective interpretations. Therefore, it is reasonable that a private firm might influence the number of assistance hours. A representative of the private firm might, for instance, assistance the user with a formal application. A representative can justify the user's need for more hours and argue that the current assistance is not enough for good living conditions. Further, a representative of the service provider can participate and represent the user in her/his contact with the Swedish Social Insurance Agency (RiR, 2004:7).

If a users is unsatisfied with a decision of the Swedish Social Insurance Agency, he/she can appeal to an administrative court, which is common (RiR, 2004:7). Several private firms (e.g. Assistansia, 2007; Livs Anda Vård och Assistans, 2008; LSS Partner, 2008; Argolis, 2008) stated on their homepages that they support users with judicial expertise and contacts with relevant authorities. One provider promoted their firm using the following statement: "If necessary, we appeal to the highest administrative court to maximize the number of assistance hours" (Assistansia, 2003).

The present study did not find that users with user-cooperatives had systematically received more assistance hours than users with municipal providers. According to Figure 2, a user with a user-cooperative service provider received more hours compared to an average user with a municipal service provider, but the panel data analysis show that the observed differences are explained by variance specific to the individual and not by the type of service provider. The fundamental objective of a user-cooperative is to provide good assistance to its members rather than to maximize profits. A member of a user-cooperative might have different roles (for instance owner and user), which sometimes are in conflict (Jacobsson, 2007). It could be that user-cooperatives view personal assistance in a long-term perspective, which will influence their incitements to increase the number of assistance hours. All too rapid an expansion of numbers of hours and thereby direct societal costs of personal assistance could call the entire reform into question.

The present study contributes to our understanding of the privatisation of public services and voucher systems in general. Proponents of voucher systems usually point out increased freedom for citizens to choose between different alternatives, maintaining that market forces will weed out inefficient providers (Lynn, 1989; National Bureau of Economic Research, 1999). More consumer power and better customer-tailored assistance were also the arguments for a voucher system of Swedish personal assistance (SOU 1991: 46). Critics of voucher systems point out the risk of “cream-skimming” and deleterious effects on poorer and less attractive customers. In 1991, this was also the only risk the Disability Commission reported when they considered a voucher system of Swedish personal assistance. (SOU 1991:46). The present study has shed light on a new aspect of voucher systems, which may appear when the providers have incitements and possibilities to influence the value (e.g. the number of hours for a specific customer) of the voucher.

The present study has a number of limitations. First, it would have been interesting to investigate how the incitements of different service providers have varied during the period 1994 – 2006. Unfortunately, we had too few observations to analyze the trend of different service providers. Considering the available data, such an analysis would have required more changes in number of assistance hours within individuals and more equal size of subgroups (i.e. service providers). A change of assistance hours over the years for an average user was uncommon, and therefore a division of the panel in shorter periods was unmotivated. The sub-group of users with user-cooperative service providers only corresponded to 504 observations, and was therefore too small to motivate a division into different periods. To be answered, our research questions required the whole panel, from 1994 to 2006. To investigate trends of different providers, we recommend a larger sample than users in the municipality of Gothenburg.

Second, from the data available at the Swedish Social Insurance Agency, it was not possible to distinguish users with private firms as service providers and users who arrange their personal assistance themselves. However, the number of users who arrange their service themselves has been such a small group, approximately 3 percent (RiR, 2004:7), that we do not think they have biased our findings in a significant way.

Third, there might be differences between users of different service providers which the present study has not taken into account. Unlike the municipality, private firms are allowed to “cream skim” the market for valuable users (Act 1974:152). It is possible that the private firms “pick” users with a higher number of hours. However, it is more complicated to explain the increased number of assistance hours for private firms as providers compared to the municipality during the period 1994 – 2006 (Figure 2). It could be the case that private providers “pick” users who are more prone to increase there number of assistance hours themselves, and/or that a user who makes the decision to change service provider, also makes the decision to change other circumstances (e.g. number of assistance hours) at the same time. According to Barron, Michailakis and Söder (SOU 2000:38), active users are usually characterised by certain types of impairments. The present study has controlled for type of impairment, and the effect of 18.4 percent more assistance hours per year for private users compared to municipal users, is above and beyond the effect of impairment. We therefore conclude that type of service provider matters for the user’s number of assistance hours. To further explore the effect of the service provider, we need among other things, to analyze the users’ applications for more hours, which in principle could be done.

It is also noteworthy that impairment itself has a significant effect on number of assistance hours for a small group of users, namely for users belonging to “category 2” according to the Swedish law, Act 1993:387 (Table 1). The higher number of assistance hours for users in category 2 in the municipality of Gothenburg corresponded to the rest of Sweden. Swedish users in category 2 have 126.6 hours per week on average, while users in category 1 and 3 have 103.7 and 101.8 hours per week, respectively (Försäkringskassan, 2007).

We would like to point out that the present study measures if private firms and user-cooperatives respectively, increased the number of assistance hours relative to the municipality. It could be that the municipality actually has strong incitements of profit maximizing, or result maximizing (Hellström, 2002). We do not know if the municipality of Gothenburg as a service provider has had incitements to increase the number of hours for their users, which might explain some of the overall trend of 3 percent (Table 1). In order to explore this, we recommend qualitative interviews with representatives of the municipal service providers.

Finally, we need more research to find out what a higher number of assistance hours among users of private providers, compared to users of municipal providers, implies for the overall costs of personal assistance and the users' quality of life. It is possible that the increased number of hours of assistance is motivated for good reasons and gives a higher quality of life for the users compared to users of municipal providers. A related study shows that users are more satisfied with private providers than with municipal providers (Roos, 2009).

Whatever the case, the present study questions the fundamental intention of the Swedish personal assistance reform, i.e. that personal assistance should promote equality in living conditions. Hence, if personal assistance is provided according to service provider, and not only to needs, some users have been discriminated for a long period of time… who?

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Table 1

Summary of panel data regression analysis for variables predicting the percentage change in number of assistance hours, during the period 1994 – 2006. (N = 4564)

Variable	B	SE B	p
Constant	61.69	4.75	0.00
Demographic variables			
Gender [reference group: Women (n=2013)]			
Man (n=2551)	0.01	0.03	0.68
Age [reference group: 18 – 29 (n=1223)]			
30-39 (n=955)	0.19	0.28	0.51
40-49 (n=855)	0.31	0.03	0.35
50-59 (n=935)	0.05	0.04	0.20
60- (n=595)	0.05	0.04	0.24
Nationality [reference group: Swedish (n=3745)]			
Other than Swedish (n =819)	0.02	0.04	0.54
Type of service provider			
[reference group: Municipality (n=2076)]			
User-cooperative (n=504)	0.11	0.06	0.09
Private firm (1520)	0.18	0.03	0.00
Unknown service provider (n=464)	0.08	0.06	0.18
Type of impairment			
According to the Act			
[reference group: Category 1 (n=1100)]			
Category 2 (n=325)	0.33	0.06	0.00
Category 3 (n=3023)	0.05	0.05	0.40
According to the ICD-10 [reference group:			
Mental and behavioural disorders (n=1324)]			
External causes of morbidity (n=376)	0.05	0.72	0.47
Diseases of the nervous system (n=2304)	0.07	0.05	0.17
Diseases of the musculoskeletal system			
and connective tissue (n=328)	0.01	0.16	0.87
Other health problems (n=67)	0.37	0.13	0.01
Unspecified health problems (n=165)	0.01	0.08	0.93
Years using personal assistance (trend variable)	0.03	0.00	0.00

Note. Wald Chi2 = 346.68, p>0.00

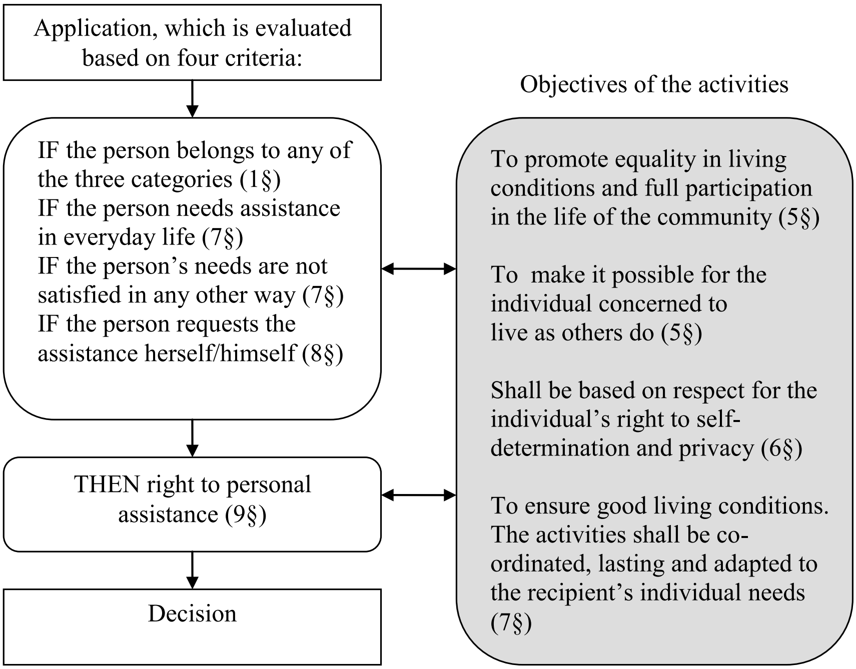
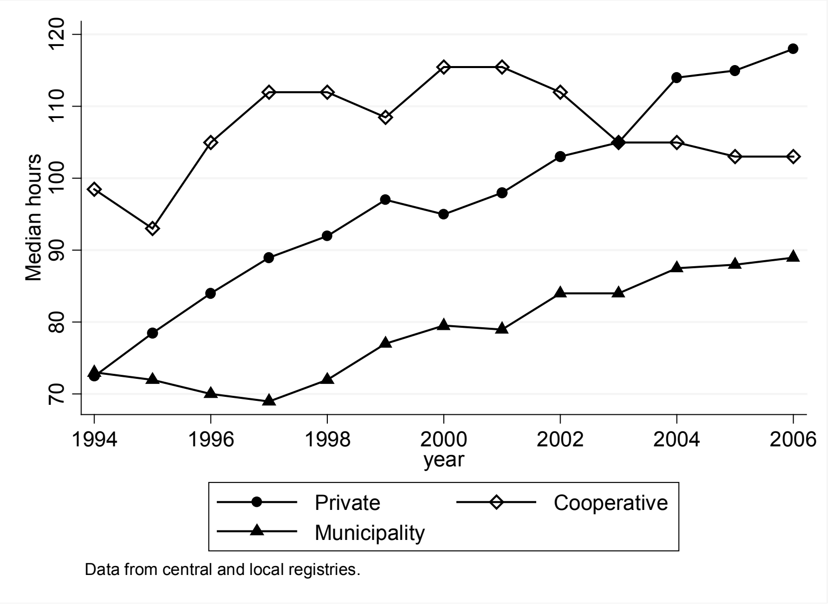


Figure 1. The administrative decision process related to personal assistance (Åström, 1998, p. 100).

Note. The paragraphs are related to ”the Act (1993:387) concerning support and service for persons with certain functional impairments”. These paragraphs are also used for decisions in the “Assistance Benefit Act (1993:389)”.



Data from central and local registries.

Figure 2. Median values of number of assistance hours by service provider and year. (Data from central and local registries of the Swedish Social Insurance Agency, November each year.)