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Enjoying Work or Burdened by it? How Personal Assistants Experience and Handle Stress at Work.

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Enjoying work or burdened by it? How personal assistants experience and handle stress at work

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ABSTRACT

A personal assistant has to promote equality in living conditions for persons with severe disabilities. The aim was to explore how personal assistants experience their work and what strategies they employ to alleviate work-related stress. Thirty personal assistants were interviewed and latent content analysis was performed. The findings regarding the experiences of work-related stress could be brought together under the theme of 'Difficulties of being in a subordinate position', whilst those regarding management strategies could be brought together under the theme of 'Coming to terms with the work situation'. There is a need of empowering personal assistants through training programmes including tailored education, working communities and coaching.

Keywords: personal assistant, disability assistance services, empowering, promote participation, work-related stress, coping, home care, adults, physical disability, qualitative interviews

INTRODUCTION

The organization and financing of the personal assistant service varies across countries, but the universal goal of disability policy is to give disabled persons the opportunity to live independently (Wang, 2007). A Cochrane review (Mayo-Wilson, Montgomery & Dennis, 2008) demonstrates that further studies are necessary to determine which models of assistance are most effective and efficient. In Sweden, the publicly financed personal assistants are a group of staff prescribed by law since 1994 for children and adults of working age with severe cognitive, mental or physical disability (*SFS* [Swedish Code of Statutes], 1993:387; *SFS*, 1993:389). There are between 50,000 and 60,000 such personal assistants in Sweden, covering a population of some 10 million (National Board of Health and Welfare, 2007). The assistance shall be tailored to the individual and shall optimize the person's influence over how the support is arranged (*SFS*, 1993:387; *SFS*, 1993:389). Accordingly, the person who is granted assistance has the right to decide what should be done by the assistant, when it should be done and how it should be done. A personal assistant might be described as a human aid, doing everything the disabled person is unable to do owing to his/her functional impairment. The personal assistant's duty is to help the disabled person with individually adapted support in daily living both within the home services and in social activities outside the home. In practice, this means that it is the task of the disabled person to manage and distribute the work of the personal assistant, and this makes the care relationship unique as compared to other types of health care. In addition, there is no special education required for working as a personal assistant (Clevnert & Johansson, 2007; *SFS*, 1993:387).

Personal assistance shall promote equality in living conditions and full participation in society, the aim being to make it possible for users "to live as others do" (*SFS*, 1993:387; *SFS*, 1993:389). Users who receive personal assistance should not live in group housing or be

cared for at an institution. Besides assistance with regard to basic needs, there shall be assistance with regard to working life, social life and leisure activities. The buzz words in political and judicial intentions are participation, integration, self-determination and equality (SFS, 1993:387; Roos, 2009). The legislation embraces an ideology inspired by the Independent Living Movement, which means empowering people against segregation and insisting that access to personal assistance over which they have control is a civil rights issue (Morris, 1997; Roos, 2009). However, Nosek (1993) found that the quality of the contributions made by personal assistants stood in relation to the health situation of the disabled persons. The importance of mutuality in close care situations in general has been stressed (Matsuda, Clark, Schopp, Mokolke & Hagglund 2005; Mattson-Prince, 1997; Nolan, Gordon & Keady, 1996). Denton and colleagues studied home care workers and found that heavy workload, difficult clients and low level of control over work were associated with poorer health (Denton, Zeytinoglu & Davies, 2002).

Our literature review concerning paid personal assistants for adult persons with physical disabilities revealed that the research, for the most part carried out in the USA, is mainly from the users' perspective and concerns financial issues and the evaluation of different models of personal assistance. The international published studies (excluding the current research group) from the personal assistants' perspective are mainly pilot studies or concern only a small sample (Clark, Hagglund & Stout, 2004; Gibson, Brooks, DeMatteo & King, 2009; Lindholm, Nodlycke & Mårtensson, 2005; Matsuda et al., 2005; Ungerson, 1999; Wang, 2007). However, there are many government documents, also some research published nationally, which are not available to the international research society (Mayo-Wilson et al., 2008). Lindholm and colleagues (2005) drew attention to the importance of personal assistants for disabled persons, but also pointed out the difficulties involved in building trust and good

relations. Wang (2007) investigated experiences of a Visual Assistant Service, a project not falling within the scope of Western ideas of personal assistance. The findings revealed that assistants have worries about their work conditions and unpredictable tasks which may be relevant for Western personal assistants as well. The limitation of knowledge regarding the personal assistant service from the perspective of the assistants themselves forms an obstacle to the development of a training and support programme for this new group of professionals. With the aim of acquiring deeper knowledge of the service provided in personal assistance, this study has focused on how personal assistants experience their work and how they handle work-related problems.

Aim

The aim was to explore how personal assistants experience their work and what strategies they employ to alleviate work-related stress.

METHOD

Design and setting

The study design was qualitative and descriptive, based on in-depth interviews with personal assistants. The study was part of a comprehensive project focusing on personal assistance and the life-conditions of adult persons (18–64 years) with severe neurological disease who were receiving personal assistance. The adult persons were identified through the county council's rehabilitation service, the municipalities' welfare service and two private units for personal assistance covering all residents with major and enduring disability caused by neurological disease or injury in the county (nearly 274,000 inhabitants). The diagnoses and demographic characteristics of the persons with disabilities who received personal assistance have been presented in previous papers (Ahlström 2006, Ahlström 2007). The persons with disabilities

received personal assistance between 5 and 24 hours a day. All needed help with personal hygiene, cooking, washing, cleaning, shopping and transportation.

Participants and procedure

Thirty persons with permanent severe disabilities who had participated in previous studies (Ahlström 2006, Ahlström 2007) were asked whether they were willing to let us contact one of their personal assistants regarding participation in the study. All of them were willing to do so, and each gave the name and address of one assistant. All the assistants in question received a letter containing information about the study. After 3–5 days they were contacted by telephone, offered more information and asked whether they were willing to participate. The sample covered 30 personal assistants, of those were 24 women (80%) and 6 men (20%). The age range was 22–55 years and the average age was 39. The average duration of working as a personal assistant was 3 years (range 3 months–10 years). Seven (23%) had had no previous experience of care work, whilst the other 23 (77%) had qualifications in nursing/health care or had previously worked in the field.

Data collection and ethical considerations

All interviews were conducted face-to-face by a trained research assistant using an interview guide and supervised by the first author (GA). The personal assistants were encouraged to narrate their own experiences of the work. The interviews included the following content areas covered through a few open-ended questions: daily work on an ordinary day and an unusual day; relation to the disabled person; problems related to the work and how they are coped with. The participants' answers regarding particular areas of experience were followed up with additional questions to obtain a closer description of thoughts, emotions and actions. This strategy allowed the interviewees to give comprehensive descriptions of their

experiences. The interviews were performed at a research centre. The average length of the interviews was 90 minutes, and the interviews were audio-taped with the participants' permission and transcribed verbatim.

The study was approved by the relevant regional board of ethics in Sweden. Participants were told explicitly that participation was voluntary and that they had the right to withdraw at any time without giving a reason. They were informed about how the data would be handled and reported, and were assured that confidentiality would be preserved. Neither of the researchers had any earlier relation to the participants.

Data analysis

The method used was based on latent content analysis for narrative text. Content analysis focuses on human communications and is suited to research that involves eliciting meaning, interpretations, consequences and contexts (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004; Morse & Field, 1995). Content analysis has many methods depending on the purpose of the study and the nature of the narrative data (Graneheim & Lundman, 2004); therefore it is necessary to clarify the procedures used in the particular case.

The interview text was first read through several times in an attempt to grasp its overall meaning. It was read as open-mindedly as possible and then divided into units of meaning. These units were first condensed on a descriptive level, keeping close to the text. In the next step they were abstracted in codes, which involved interpretation of the underlying meaning. Through identification of similarities and dissimilarities in the units and codes, further abstraction could be achieved into sub-themes, and finally two themes were

generated (Graneheim & Lundman, 2004), one concerning problems experienced and one concerning the handling of these problems.

FINDINGS

The interviewees often started by narrating good encounters with the disabled persons they were assistants for, indicating an overriding sense of their work's having a meaning. They perceived their occupation as having a low social status, and this had influenced them. Prior to taking up this occupation they had heard a great deal of negative comment on it, but had in fact found that things were not as negative as they had heard. They felt that society should assign a higher value and status to their work. The opinion was that most assistants were women and that the recruiting of more men might give the profession a higher status. Further on in the interviews, the personal assistants spoke of the burdensome side of their work, but they also described ways of handling work-related problems.

Difficulties of being in a subordinate position

The overall theme covering work-related stress emerged as “Difficulties of being in a subordinate position”. Most of the problems described were not so much related to the person requiring care, as to the nature of the work. This is illustrated in the following seven sub-themes: *Lack of knowledge, Loneliness and missing work community, Uncomfortable situations, Employer problems, Lack of control in unstructured work, Mental pressure and lack of stimulation, Too much responsibility and overtime.*

“It’s a strain physically and mentally, because, as I said, you never know what’s going to happen — never! We’re on our own all the time and we’ve got appliances for lifting and for sucking out phlegm, and we’ve got probes, and it’d all better be in 150% working order.”

“It’s funny that you sort of haven’t got a boss to turn to as you usually have in another sort of job. You’ve got nobody to talk to. It’s tough when things get difficult and there’s not really anybody to go to.”

1. Lack of knowledge

All of the personal assistants spoke of feeling they did not have sufficient knowledge of or training in how to carry out their responsibilities satisfactorily. They wished they had more knowledge about the disabled person’s illness and the person’s medications. Some of them spoke of not knowing what kind of food would be most beneficial to the person requiring assistance. Others spoke of wishing they had received more training in caring and a longer introductory period when they entered this line of work. Taken together, these aspects had caused them to feel insecure in their profession.

2. Loneliness and missing work community

Working as a personal assistant implies working alone with the disabled person; thus personal assistants have no colleagues to work with or talk to. They described this as a sort of loneliness and reported a need to meet other people more. Some spoke of a particular need to discuss their work situation with other assistants. Others indicated a need to simply get things off their chest. There was mention of the professional rules of secrecy that keep them from talking to their family or friends about problems at work. The communication between personal assistants was felt to be too sparse to meet the needs of the situation. Furthermore, problems between personal assistants working with the same disabled person did occur at times: a personal assistant on duty might, for instance, call the one who had been on the previous shift and criticize this person for having done (or failed to do) one thing or another.

3. Uncomfortable situations

The assistants described situations that they perceived as unpleasant and that prevented them from doing good work. This could involve intimate caring situations, such as toilet visits and facing the person when he/she was naked; they felt that these situations were sometimes embarrassing both for them and the disabled person. They spoke of how their presence sometimes affected the disabled person negatively and felt this was problematic. The work was also sometimes a physical strain. When the disabled person fell, it could be very difficult to help them up. Even where technical aids were available, it was not always possible to use them. This type of situation aroused a sense of incompetence and shame in the personal assistants.

4. Employer problems

The disabled person is the work manager and the personal assistant should follow his/her wishes concerning how the work and care are carried out. This is a basic rule, nevertheless a number of the personal assistants saw it being sometimes very difficult to handle in that they wanted to do things differently, in a way they felt was easier or better. Some felt they were in an uncomfortable underdog position and that the disabled person was demanding. Several participants talked about the difficulty in not having a work manager in the personal assistant organization with whom they could discuss work problems. Others worked with a disabled person who had personal assistance 24 hours a day, and they felt it would be of value if all the assistants could get together, without the disabled person present, and discuss the work more often.

5. Lack of control in unstructured work

The assistants spoke of feeling that they had little or no control over their work situation. They found it difficult to describe an ordinary workday, as each day was very different. They reported a lack of routines in their daily work, and the work sometimes involved stressful timetables. They felt it was difficult at times to know how long they had to work on a given day, and this meant that they often felt tired and unsure. For example, they did not always know when they could take a lunch break. They felt insecure about both the disabled person and themselves, and felt a sense of frustration, irritation or discomfort in these situations which were hard to handle.

6. Mental pressure and lack of stimulation

Descriptions of sadness and feeling unhappy were common. Where it was not possible to communicate adequately with the disabled person, there was no feedback. Working an entire day and not having a conversation with another person was a mental strain. Several assistants talked about feeling empty and dissatisfied with the work because of all the mental strain of working alone, which was very intensive and demanding. The mental fatigue could cause the assistant to start looking for another job. The work did not provide enough stimulation. The assistants felt that they should not take initiatives but were there only as “tools” for the disabled person. One of them, for example, spoke of the work as simply involving being the disabled person’s arms or legs and doing things the disabled person wanted. It would be better to do work that required more physical strain, with more physical tiredness afterwards.

7. Too much responsibility and overtime

Other assistants reported that they had to assume too much responsibility. Some said that they just had to manage on their own, prioritizing tasks and doing their best despite the stress. This

was compounded by a sense of powerlessness, because they typically could not influence their work situation. Several participants felt uncertain about the quality of their own work. Others reported that they always had to solve work problems on their own. It was a commonly held opinion that being a personal assistant was hard work. Some assistants found it difficult to maintain a clear line between being a friend and being a professional. Others indicated that if a close friendship develops, it becomes more difficult to leave work at the right time, and that there may be an implicit demand to work overtime. Several personal assistants, who did not have families of their own, felt that they sometimes taken advantage of that situation.

Coming to terms with the work situation

The most important resource in handling stress was experiencing a feeling of communion with the disabled person. The participants mentioned how important “personal chemistry” is, as well as having similar interests and opinions with regard to important things in life. This lays the foundation for a proper friendship, which facilitates the work. Receiving positive feedback from the disabled person was also a resource for the personal assistant. The overall theme covering the handling of problems and stress emerged as “Coming to terms with the work situation.” There were five strategies for this: *Seeking social support*, *Trying to be professional*, *Striving to understand*, *Establishing good dialogue*, and *Creating structure as well as variation*.

“I put myself in the person’s place. I’d say I find that easy, and that’s what the chap I work for says, that I can so easily put myself into his situation as a disabled person. Yes, I can imagine just how awful his life is. He’s always had to sit on his own — couldn’t even watch TV before. Now we sit together and watch a film and have a good laugh, and then I try to sort of put it into my head that, oh yes, I’m doing something good. It’s getting better and better all the time.”

“There are several disabled people that have a personal assistant in the same building where she lives. We’ve become like a little team, and it’s pretty good to listen to others who’ve had the same experiences. It’s nice just having it confirmed that it’s not just me that’s tired. Even if I haven’t done anything special, the work can be tiring and hard going anyway.”

1. Seeking social support

The most frequently used strategy to handle the stress was to seek social support. This strategy was used in many situations, primarily as a way to solve the problem of loneliness. Seeking social support occurred when the participants encountered other personal assistants at work meetings or during the few minutes at a shift change. Telephone conversations between assistants were also mentioned as a way of seeking social support. They felt that knowing they were not alone in their work problems was important and helped them “charge their batteries.” Discussions and meetings with colleagues gave inspiration and allowed an exchange of ideas. The assistants mentioned that good communication between personal assistants helped them do good work. Improved communication with colleagues was something they wanted.

2. Trying to be professional

Acting in a professional manner was described as doing things correctly and solving problems in daily work as well as one could. Many times this involved understanding that some kinds of work had to be done even though they were not pleasant. Some participants stressed the importance of understanding that the disabled person is the job manager and that being professional means letting the disabled person make decisions about daily activities and how they should be performed. Flexibility and patience were regarded as important qualities, for example treating the disabled person with respect and dignity and not arguing too much or acting against the person’s will. Furthermore, in situations where the personal assistants did

not have enough knowledge to solve a problem, they had to find a solution anyway. They would most frequently call someone with more knowledge or try to find an answer in books. Some of the personal assistants had a nursing assistant education and/or had worked in a hospital, and this they felt was of great benefit to them, especially as compared to colleagues without such a background.

3. Striving to understand

Being able to adopt another person's perspective made it possible to imagine how the disabled person thought and felt in specific situations. This ability helped one meet the person's needs. An example mentioned concerned the idea of being naked in front of others. The personal assistants reported feeling both empathy with and sympathy for the disabled person when they themselves being in his/her situation. Having had a rich experience of life was seen as an advantage. If one had met people with problems in other situations or faced problems oneself, it made it easier to understand the disabled person's needs and situation. The assistants perceived their own crises as having made them stronger.

4. Establishing good dialogue

In this strategy, there was discussion with the disabled person when a problem arose, and through discussion it was possible to find a solution acceptable to both parties. According to several personal assistants, politely confronting the disabled person, instead of simply being quiet and acceptant, was one way of coming to an agreement. Expressions of appreciation from the disabled person made the work easier for the personal assistant. Positive feedback from the disabled person resulted in a better relationship. In addition, joking about difficult and embarrassing things was described as one way to handle them.

5. Creating structure as well as variation

Creating routines and making plans jointly was one way to try to deal with expected problematic situations. For example, if the disabled person has difficulty swallowing, it is necessary for him/her to sit in the right position during a meal. One way to decrease gloominess and monotony was to create variation in work tasks by finding new things to do. Being active was also a strategy used to reduce tiredness. Some participants felt it was a good idea to work as a personal assistant for two disabled persons, alternating between them. Some personal assistants reported handling work-related stress by engaging in different kinds of work as well as by relaxing and doing things they liked in their free time.

DISCUSSION

Against the background of the scarcity of literature in English on the subject of personal assistance from the assistant's perspective, our findings have an important role to play with regard to improving the personal assistance services. The study revealed that the personal assistants enjoyed and were fairly satisfied with their work but at the same time perceived the work as "Difficulties of being in a subordinate position". Similar findings were reported by Clark and colleagues, who found that the personal assistants reported high levels of satisfaction with their relationship with their employers and with their jobs in general, despite dissatisfaction about low salary (Clark et al., 2004). In our study the personal assistants experienced a variety of problems in their work and reported different kinds of strategies to handle these problems. Their work satisfaction and their strategies for handling work-related stress can be summarized as "Coming to terms with the work situation".

All the personal assistants in the present study asked for more knowledge which would enable them to better perform their work. However, a major subject of debate has been whether the

education of personal assistants would lead to an improvement for the disabled person (Stevens, 2009). The origin of this debate is to be found in the meaning of the concept of empowerment as opposed to the concept of caring. The ideology behind personal assistance is empowerment, meaning the maximization of choice and control for the persons with disability in his/her everyday life. Caring is used mostly in the sense of taking responsibility for, and the people are assumed to be unable to exert choice and control (Morris 1997). But the debate has tapered off in the last ten years or so because of the increased focus on empowerment in the context of caring as well (Gibson, 1991; McCarthy & Holbrook Freeman, 2008). Gibson (1991, p. 359) offered an early redefinition of empowerment within nursing as “a social process of recognizing, promoting, and enhancing people’s abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives.” However, the present study indicates that the issue of empowerment should involve not only the disabled persons but also the personal assistants. One suggestion is that personal assistants who experience more empowerment are more proficient in incorporating this in their support for persons with severe disability. It is important that this should be investigated in future research in order to acquire deeper knowledge about the quality of personal assistance.

The present study has generated deeper knowledge concerning how personal assistants experience their work and how they handle work-related problems. It has shown that the personal assistants feel a need for more education, which is in accordance with findings from other studies (Lindholm et al., 2005; Matsuda et al., 2005). More opportunities to attend seminars where they can learn and share their experiences with other personal assistants could be a way to reduce experiences of stress in their work situation. We therefore agree with Stout and colleagues (Stout, Hagglund & Clark, 2008), who emphasized the need for career

development programmes and support systems, such as personal assistance training and accreditation for personal assistants, the idea being that this could raise the status of the position of personal assistant. The low status of this occupation has been mentioned as a problem in several studies (Coogle, Jablonski, Rachel & Parham, 2008; Denton et al., 2002; Gibson et al., 2009; Matsuda et al., 2005). The above discussion focused on the fact that personal assistants want to have more knowledge and training, but there is also a need to take into consideration what the content of the training should be. Both Schopp and colleagues (Schopp, Clark, Hagglund, Mokolke, Stout & Mazurek, 2007) and Coogle and colleagues (2008) have developed and evaluated training programmes for personal assistants, but more studies are needed. The personal assistants in this study expressed the need of tailored education and training focused on the person with disability the assistant they were currently working for. We believe that, when planning educational programmes, it is necessary to take into consideration both personal assistants' and disabled persons' wishes concerning the competence and education of personal assistants.

The most frequently used strategy was seeking social support, and this was employed in various problematic situations. One interpretation is that seeking social support is one way of acquiring more knowledge or acquiring confirmation that what one is doing is appropriate. Seeking social support is a commonly applied strategy in handling different types of distress and is included in the most widely used instrument to assess coping, the Ways of Coping Questionnaire, which explains the amount of knowledge in this area (Parker, Endler & Bagby, 1993). In addition, social support from a theoretical perspective has been a huge research area in social science for many years.

The personal assistants' descriptions show that they are aware of the intention of the law (*SFS*, 1993:387), which is that disabled persons are to receive assistance and support that are tailored to the individual to the greatest extent possible and that disabled persons are to have influence and direct power over the organization of their assistance. This finding is in accordance with the results of other studies (Gibson et al., 2009; Lindholm et al., 2005). However, the participants also experienced problems related to the above-mentioned intention of the law. What is unique about working as a personal assistant is that one works alone in the home of another person, who is one's work manager. For this reason, personal assistants' ability to influence their work situation is highly dependent on their relationship to the disabled person. As in other studies (Denton et al., 2002; Matsuda et al., 2005), personal assistants reported relationship problems when disabled persons were demanding consumers, and some mentioned the risk of burnout. This could be one explanation of the high rate of termination among personal assistants. Several Swedish evaluations have revealed something in the nature of a 40–60% annual turnover of personal assistants in the towns (National Board of Health and Welfare, 2007).

Although the focus of the present study was on problems experienced by personal assistants in their work, it is important to remember that the personal assistants were in many ways satisfied with their occupation and spoke of having had good encounters with the disabled persons as well as an overriding sense of their work's having a meaning. This is in line with previous findings in the literature (Gibson et al., 2009; Matsuda et al., 2005). Matsuda and colleagues (2005) drew attention to the fact that, for personal assistants, more than for any other profession, the working relationship between the disabled person and the assistant is dependent on social capital. This social capital is acquired through investment in a relationship with the person they work for and whose needs they serve (Coleman, 1988).

The present results could also be discussed in relation to studies of disabled persons' opinions about personal assistants. Results from such studies have shown that a good relationship is very important (Ahlstrom, 2006; Ahlstrom & Wadensten, 2009; Matsuda et al., 2005; Wadensten & Ahlstrom, 2009a; Wadensten & Ahlstrom, 2009b). Marquis and Jackson (2000) found that the interpersonal qualities of personal assistants are more important to the disabled person than their technical skills are. Disabled persons receiving personal assistance have emphasized that it is very important to feel that they have control over everyday life (Ahlstrom, 2006; Meyer, Donnelly & Weerakoon, 2007; Wadensten & Ahlstrom, 2009b). Our further studies will focus on personal assistants' possibilities of applying ethical principles, which are the cornerstone of the Swedish legislation, in their practical work.

Large-scale assistance is becoming increasingly common in Europe, above all in the Scandinavian countries. The provision of personal assistance in Sweden is increasing both in terms of number of recipients and in terms of average number of hours per recipient. This means ever-higher costs for both the central government and the municipalities since the start in 1994 (Roos, 2009). Against this background, greater knowledge about personal assistance from different perspectives is clearly of great interest for society. However, the legislation and organization of the personal assistant service are different across countries, and this may influence the relation between disabled persons and personal assistants (Clevnert & Johansson, 2007; Mayo-Wilson et al., 2008; Wang, 2007). This should be considered when interpreting results from studies performed in different countries.

Method discussion

Content analysis was decided upon in order to keep the possibilities open for interpretation at various content levels. Some of the personal assistants gave comprehensive and rich stories whilst others had difficulty in expressing themselves, especially with regard to the way they handle work-related stress. This means that a method that allowed analysis of both manifest and latent content had the merit of including all the participants' voices in the results. This was considered a matter of trustworthiness (Lincoln & Guba, 1985). In sum, the content analysis was a systematic process of identifying the patterns of meaning in the context and messages in the narratives, by grouping units of meaning, labelling, classifying and developing sub-themes and themes (Graneheim & Lundman, 2004). However, no univocal connection between problems and management strategies was apparent in the data. This is not surprising in view of the character of the interviews where the researcher put a few broad open-ended questions in order to obtain answers as rich as possible.

Conclusion

The present study has revealed that the personal assistants experienced a variety of problems in their work, summed up as 'Difficulties of being in a subordinate position'. However, they applied several strategies, summarized as "Coming to terms with the work situation" to handle the work-related stress. The findings indicate that these strategies lead to reasonable satisfaction with the work situation. The study has also shown that personal assistants request more education, a working community and support in problematic situations. The education needs both to be tailored to the person they are working and to provide general knowledge about their professional role in strengthening autonomy, integrity and participation in persons with severe disabilities. Collaboration in the education with stakeholders and representatives of associations for persons with disabilities can help to see to it that the perspective remains

that of the person with disability, and that this person is treated with respect. The challenge is to comply with the assistant's request for the knowledge needed in order to provide the best possible assistance. This knowledge, concerning the disease and its consequences, shall not be overly medical in nature but shall be directed towards the goal of enabling the person with disability to maintain control over their everyday life. Here the social worker has an important part to play in coaching the personal assistant. For the person with disability there shall be equality in living conditions and full participation in society: he or she shall be able to "live as others do". Further studies are needed to empirically test effective methods of providing personal assistance training programmes and of empowering personal assistants.

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