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Risky business? Organizing sexual facilitation in Swedish personal assistance services

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ABSTRACT

Despite nearly two decades of disability research highlighting the need to take greater account of disabled people's sexualities, sexuality is still largely a taboo subject in disability services, thus limiting service users' possibilities to express their sexuality. In this article, I aim to show how Swedish personal assistance managers organize sexual facilitation, that is, assistance from personnel in service users' sexual engagement. The article draws on findings from a focus group study with managers of municipal and private service providers. Three main themes are discussed: the managers' different ways of organizing sexual facilitation; how they conceptualize sexuality and normality; and risk management practices. I argue that societal discourse on sexual normality greatly influences managers' views on and strategies for organizing sexual facilitation. Hence, sexual facilitation in personal assistance services is viewed as a non-normative form of sexuality and a work-related risk rather than a possibility to increase service users' sexual rights.

Introduction

Ever since the publication of the seminal work *The Sexual Politics of Disability* (Shakespeare, Gillespie-Sells, and Davies 1996) concerning the sexual lives of disabled people, issues around sexuality have been on the disability studies agenda. One of the most significant contributions of this work, and much of the work that has built on it, is the move from a medical understanding of disability to an understanding that also includes social, cultural, socio-economic and political aspects (Shuttleworth 2010). Similarly, sexuality studies have increasingly focused sexual identities and practices as social and political concepts rather than merely biological ones (Weeks 2010). The core of these parallel developments is the challenging of notions of sexual and bodily normality.

Needless to say, a plethora of research studies challenge any historical as well as currently still widely held beliefs in lay consciousness that disabled people lack sexual identity, ability and desirability. However, one aspect left largely unexplored is the issue of disabled people's actual sexual engagement. What happens when we move beyond simply theorizing sexual identity and access for disabled people, and start discussing how sexual engagement is to take place in practice? Depending on the context, the answer will differ. In disability services as well as in other, similar services, a growing issue of concern for service users is how to engage in sexual activity, often termed as a private matter, when living with around-the-clock services, often a public matter (Browne and Russell 2005; Shuttleworth et al. 2010). The issue can be especially delicate if there is a need for sexual facilitation, that is, assistance from personnel in service users' sexual activity.

Few studies have investigated sexuality issues in personal assistance services, specifically for mobility-disabled service users. A more well-researched area is, for example, group homes for intellectually disabled service users (Hamilton 2009). One main concern often highlighted is how to negotiate, for instance, issues of consent versus safety. Regarding mobility-disabled service users without intellectual disabilities, the issue of consent is not acute in the same manner. However, many other issues are shared, for example, the taboo surrounding disability and sexuality, leading to service users and personnel experiencing difficulties in handling situations where such issues arise.

Previous research show that sexual facilitation is a morally and ethically complex area of services for both service users and personal assistants (Bahner 2012, 2013). It has been suggested that these difficulties may be due to absence of adequate staff training in sexuality issues (Boyle 1993), on the one hand, and of policies and/or guidelines, on the other (Couldrick and Cowan 2013). Since managers are responsible for providing such, it is of value to explore how managers actually organize personal assistance with regard to different aspects of service users' sexual lives.

Therefore, the aim of this article is threefold: first, to study how managers of Swedish personal assistance services *conceptualize* sexual facilitation and what values and norms emerge from their discussions; second, to investigate how they *organize* sexual facilitation for mobility-disabled service users; and third, to explore possible *consequences* in practice, for services users and assistants, of the managers' expressed values as well as of their specific ways of organizing sexual facilitation.

Personal assistance services and the silence of sexuality

In Sweden, personal assistance is an individual right granted by the LSS law (SFS 1993:387). To be eligible, applicants must, among other things, have *basic needs* for assistance for a minimum of 20 hours per week, which include help such as managing hygiene and meals, dressing and undressing, and communicating with others. In addition, eligible service users can apply for assistance with *other personal needs*, such as household duties, leisure activities, and assistance at work or with studies. Service providers include municipalities, user-led cooperatives, private companies and service users managing services themselves.

Services are based on an independent living ideology and aim to make it possible for service users to live in the community 'under good living conditions' and on the same terms as enjoyed by non-disabled individuals, according to the LSS law's guiding principles of autonomy, integrity and self-determination. Furthermore, the services aim to move from what service users formerly experienced as professional dominance to user influence and authority, making evident an ideological shift in service provision from *care* to *assistance*. Services are therefore individually outlined based on the service users' wishes regarding whom to employ as assistants, which services are required and how they should be executed.

However, service providers may have specific conditions for the use of direct payments (Askheim 2005). Furthermore, local political or bureaucratic interpretations of needs and the meaning of service user influence may result in differences in service provision (Lewin, Westin, and Lewin 2008). Consequently, despite national policy goals, how managers choose to organize the services is influential, since they define, structure and uphold the organisational norms (Scott 2008), giving them a power advantage over service users (Hugemark 1998), legitimated in terms of professional discretion (Lipsky 2010).

Sexual facilitation: ambiguity between policy and practice?

Sexual facilitation is the personal assistance required for service users to be able to express their sexuality as desired. This may include a wide range of activities:

> Providing accessible information, fostering an environment which allows intimacy, offering and observing need
> for privacy, encouraging and enabling social interaction, the procurement of sexual goods, arranging paid-for

sexual services, facilitation of masturbation or sexual intercourse with another party (undressing, handling of aids, positioning) and sexual surrogacy. (Earle 2001, 437, see also Mona 2003)

Neither the law nor the preparatory works mention sexuality, resulting in sexual facilitation being unregulated in Swedish personal assistance services. Service users and personal assistants are left to negotiate such conditions among themselves, unless the manager has decided to give instructions, which rarely happens (Kulick and Rydström 2015). In previous research studying service users' and assistants' experiences of sexual facilitation, this lack of guidance has been high-lighted as one of the problematic aspects surrounding this issue (Bahner 2012, 2013). This is in contrast to the situation in Denmark, where social policy provides the prerequisites for including sexual facilitation in the services, and where the National Board of Social Services has developed methods for working with this in practice through specific guidelines and training (Socialstyrelsen 2012b).

In Sweden, the topic of sexuality and disability is largely taboo, impeding constructive discussion about how sexual facilitation could be organized – if at all discussed as an option (Kulick and Rydström 2015). One reason for this difficulty is the law against purchase of sexual favours. Many inter-pret this law as hindering sexual facilitation, since personal assistants are paid to execute services. Consequently, arranging paid-for sexual services or sexual surrogacy is not an option; however, the remaining options are rarely discussed either.

Nevertheless, there have been signs of an emerging interest in discussing sexual facilitation, at least from one service user organisation. The Swedish Federation of Youth with Mobility Impairments (*Förbundet Unga Rörelsehindrade*) has published a handbook for service users and personal assistants that aims to break the taboos surrounding sexuality and personal assistance, as well as give advice on how to organize sexual facilitation (Svensk 2011). Furthermore, the Swedish National Board of Health and Welfare (Socialstyrelsen) have commented on certain cases of sexual facilitation through their Social Committee. The Committee have issued statements discussing how sexual facilitation such as assistance with masturbation in disability services (Socialstyrelsen 2012a) and in formal elder care (Socialstyrelsen 2011) can be handled in practice and without crossing legal or professional boundaries. Nevertheless, these documents are largely unknown to service users as well as to professionals.[1]

Managing personal assistance services: sexuality as a risk

Sexuality is a complex phenomenon shaped by economic, legal and political structures in a specific social, cultural and historical context (Weeks 2010). Furthermore, sexuality is related to dimensions of power, such as gender, disability, age, ethnicity and class. Despite Sweden being at the forefront of abortion rights, LGBT rights, compulsory sex education in schools and free youth guidance centres, among other things, neither the LSS law nor the preparatory works at all mention sexu-ality. Disabled people's potential special needs in these areas are often neglected, for example, regarding physical accessibility and appropriate competency in sexual health care. Shildrick (2007) holds that one reason for this reluctance to acknowledge *as well as* implement sexual rights for disabled people is that disability and sexuality are considered a *dangerous discourse*, linked to anxiety and discomfort with differential embodiment of sexuality and erotic manifes-tations. Similarly, Mollow and McRuer (2012) argue that pity and fear are the feelings most often associated with disabled people's sexuality, and moreover, that they are seen neither as sub-jects nor objects of sexual desires and practices.

Rubin (1984) offers an explanation for this *sex negativity*, that is, reasons why the topic of sexuality in Western cultures is so infused with discomfort and fear. Stemming from traditional Christian values, sexual activity is seen as essentially sinful, dangerous and destructive. Consequently, a *hierarchical valuation of sexual acts* has developed, influencing definitions of 'normal' sexuality – rarely including aspects such as sexual engagement involving professionals such as personal assistants, hence

stigmatizing those who do not fit into this norm. The efficacy of this framework is built up around the constant need to 'draw the line' between what is acceptable and what is not, and this (imaginary) line constitutes the boundary between sexual order and chaos. The need to draw such boundaries is based on fears of what Rubin (Rubin 1984, 171) characterizes as *the domino theory of sexual peril*: '(e)ven when an activity is acknowledged to be harmless, it may be banned because it is alleged to "lead" to something ostensibly worse' – in other words, a risk.

Regarding risk as a social construction is therefore useful in understanding managers' reactions to the issue of sexual facilitation (Kemshall 2002). Often, personal values and normative assumptions – rather than merely an objective probability of something happening or not – highly influence risk assessment (Kemshall 2002) – sanctioned within the scope of professional discretion (Molander and Grimen 2010). Consequently, 'the social construction of risk must engage with the social construction of management practices to govern risk', and the attention is directed away from risk per se and instead 'towards the role of managerial and administrative practices organized for the explicit purpose of representing and handling risk' (Power 2007, 20, 4). In other words, regarding sexual facilitation as a risk in personal assistance services appears logical from the managers' perspective when taking the above notions into account.

Focus group discussions

This article is based on three focus group discussions held in 2013 with 10 managers of municipal and private personal assistance service providers in Gothenburg, Sweden. The aim of collecting data through focus groups was threefold. Firstly, the exploratory character of the present study is suitable for this method (Barbour 2007) since there are no former studies where managers of personal assistance services discuss sexuality issues. Secondly, some may experience the topic of sexuality as sensitive or normative, making it easier to discuss in a group of peers than alone with a researcher in an interview (Morgan 1997). Thirdly, with regard to the general working situation of managers – namely, that they have few opportunities for meeting other managers to discuss their work – there is a potential positive impact for participants in sharing experiences (Kitzinger and Barbour 1999).

I recruited participants via email or by telephone. As a result, three groups consisting of three to four managers (A1–3, B1–4, C1–3) convened: eight women and two men aged 31–53 years who had been working in managerial positions for 1½–7 years. Normally, focus groups consist of up to 12 participants; however, small groups are advantageous if the topic of discussion is complex and/or if the participants have high positions (such as managers) wanting enough time to express their views (Morgan 1997). Focus group discussions lasted for between 90 and 120 minutes and took place at the university. The discussions were audiotaped after participants gave informed consent. I guaranteed participants anonymity with regard to the published material and ensured that their name as well as the name of their workplaces would be excluded. However, I could not assure within-group anonymity and participants therefore agreed to keep in the group what was said in the group – something that can never be controlled in practice, but may support participants' interaction in the focus group situation.

As a moderator, I tried to facilitate every participant's involvement and validate a variety of views rather than control the discussion (Bloor et al. 2001). To stay on track, I relied on a topic guide including themes such as the concept of sexuality and sexual boundaries, and management practices concerning sexual facilitation. Ending each session, the groups discussed a set of vignettes dealing with hypothetical situations of sexual facilitation. The vignettes were deliberately vaguely written so as to act as a stimulus for discussion (Bloor et al. 2001)

In the following, group interaction data are highlighted as follows: *italics* indicate speaker emphasis using tone of voice, (mm) indicates other participants humming in agreement with the speaker, … indicates a short pause, and (…) indicates that a quotation has been shortened.

Analysis

A focus group discussion is a highly contextual and specific setting, a site of performance where participants take on different roles and a group dynamic evolves (Smithson 2000). Myers and Macnaghten (1999, 174) call this 'the situatedness of opinion', a notion that is in line with the study's epistemological approach, an approach Halkier (2010) terms a 'moderate social constructivist perspective'.

I transcribed the focus group discussions verbatim in separate Word documents, and analysed the prints manually. Overall, I used an abductive approach to guide my analysis. While transcribing the discussions, I began an initial analysis by highlighting main themes in the material. In a second stage, I performed a more comprehensive mapping of themes according to a content analysis approach (Patton 2002), resulting in three themes: how managers organize sexual facilitation; how they conceptualize sexuality; and risk management practices. In parallel, I performed a mapping of group interaction, including agreement, disagreement or joking, as a base for the third stage where an analysis of the content of the discussions in relation to the way topics were discussed. Duggleby (2005) has termed this a congruent methodological approach as an analysis of interaction data can support the content analysis and provide new levels of insight to the phenomenon under study. The fourth stage of analysis yielded new questions and new strategies that managers used to legitimize their specific way of dealing with sexual facilitation: repression, displacement, and reformulation. Finally, I applied the chosen theoretical perspectives to understand the relations between themes and strategies.

Sexual facilitation in practice: a narrow framework

Only one of the managers in this study provided their organisations with general guidelines or policies concerning sexual facilitation. Participant A3 had started to mention sexuality in the introduction to newly employed personal assistants – a proactive strategy. In group B, managers started laughing when I asked about it. They began discussing how their heavy workloads prevented them from working with such issues when they were responsible for the budget, administration and employees – issues requiring more immediate attention. One participant also said that 'assistants have great respect concerning sexual integrity' and that they do not really discuss any issues that 'we [managers] do not have anything to do with'. It was also suggested that the Swedish Social Insurance Agency, when assessing eligibility for personal assistance services, should include needs concerning sexuality as well, since this would force personal assistance providers to organize services covering that area of life. Using the lack of municipal guidelines and heavy workloads as excuse, and regarding sexual facilitation as a peripheral issue, are strategies of displacement as well as of repression, as they do not recognize responsibility for sexual facilitation, and move focus to other issues that are seen as more important. On the other hand, since sexual facilitation is not regulated, they are unlikely to face any blame for not organizing it.

In group C, however, one of the participants talked about a service user who was open about her sexual needs in terms of turning to her assistants for help. The service user said that she longed for a man and the assistants asked the manager how they should assist. The manager arranged a meeting, after which they agreed to provide assistance by buying sexual aids, and helping with preparations in order for her to be able to masturbate on her own. They also agreed on some preconditions such as that the service user could choose which particular assistants to involve, thus excluding substitutes, for example. In this case, the manager reinterpreted the service user's longing for a man as a need for masturbation and sexual aids, perhaps because she thought this would be easier to organize than arranging for the service user to actually meet a man. The strategy is also individualistic, since she did not provide general organisational guidelines.

The manager was very content with how the situation was handled:

C2: Since the assistants didn't have any objections to it and since it was her [the service user's] wish, we only saw it as part of her needs (mm). And because this help was

nothing more than we do when helping someone with a catheter I didn't think it was anything to worry about.

C1: But it seems like the group had great maturity in that, to be able to, somewhere …

C2: Yes, it was women aged between 35 and 40 (mm) and they had known her for a few years, and liked her, and overall it was a fun and nice work environment (mm) so they didn't have any problem with it *at all*.

The relationship between the service user and her assistants was described as well functioning, which was useful in dealing with sexual facilitation, a fact that has been described to be of value in other intimate situations as well (Egard 2010). Another aspect in focus was the assistants' age and/or maturity. Handling sexuality was considered to require a certain competence; however, para-doxically, the managers did not seem to offer any training to prepare all assistants to be able to gain such competence in handling situations like these adequately. Instead, they simply viewed this com-petency as a skill based on life experiences, which can be regarded as a displacement strategy.

Sexual engagement: moral boundaries and cultural understandings

A recurrent theme in all discussions was the definition of sexuality, and, following this, where the boundaries around sexual facilitation ought to be drawn. In all three groups, the participants in some way or another discussed sexuality in relation to the LSS law, and more specifically in relation to the eligibility criteria defined as 'basic needs' as opposed to 'other needs' (SFS 1993:387). In one group, the participants agreed that sexuality is a basic need, since it is defined as such by the World Health Organization (WHO 2006), while in another group, it was considered as other need, since sexuality is not mentioned as a basic need in the LSS law. Overall, the discussions pointed to a general uncertainty in how to interpret the LSS law with regards to sexual facilitation being included or not.

The discussions also touched on definitions of sexuality as something private and intimate, and a taboo subject in society as a whole – highlighting an awareness of the managers' roles being public and therefore having to attune their actions to public discourse. The individuality of sexuality was also emphasized:

Researcher (J.B.): How do you regard sexuality as such? Earlier on you discussed whether it should be regarded as a basic need or …

A3: I mean, at this point you're influenced by what the legislation says, since you've been working with it for such a long time.

A1: What's difficult is, whether it's basic or other, is … it has to be individual (mm)! I mean, eating, and basic needs such as dressing and hygiene are concrete things that are observable. If you don't do anything about it, it might make it hard to be part of society (mm) or to get out, or if I don't eat I can't survive. But sexuality is so individual for every single person (mm) regardless of disability (mm) so it's really hard to tell *what* it is. And then the question arises: who should decide then (mm)? (…)

A3: And especially since sexuality is so different for everyone … I mean for some it might be about reading something about sexuality and for others it's an actual action. There I think (mm) it's hard to decide.

A1: Yes, when can the need be said to be taken care of (yes, mm) actually?

The difficulty to define sexuality therefore appeared to influence the managers' perception of the possibility to formally organize sexual facilitation, as well as their insecurity in knowing 'who should decide' about such definitions. Seeing themselves as the person who should make such definitions

seemed unrealistic – a displacement strategy. Management by non-recognition (Shildrick 2007) becomes visible and can also be understood as a process of restricting disabled people's 'sexual access' (Shuttleworth 2010). This further highlights the ambivalence in social policy, since other areas such as accessibility, education and work are very explicitly regulated (Shildrick 2007).

Sexuality for whom?

In all three groups, there was also discussion about the direction of the service user's sexual expression – that is, cases where a service user objectifies the personal assistant, compared to instances where they direct the attention towards a partner or themselves. In these discussions, the managers drew firm boundaries, not accepting the former behaviour. Participants shared examples of cases of male, middle-aged service users directing their sexual expression towards their young female personal assistants. The assistants discussed were described as inexperienced, weak and vulnerable, while the service users were described as abusive, manipulative and sexually frustrated. Managers' strategies for dealing with such situations were to have a talk with the service users, and if this did not help, they refused to employ young women as assistants for them. In these situations, managers overrode the service users' legal rights to self-determination and autonomy in deciding whom to hire, since they judged the personal assistants' rights to an adequate work environment as more important, for example in terms of avoiding risk of sexual harassment. In other words, they used a strategy of reformulating the problem. Personal assistants have in fact expressed concerns in previous studies for such situation; however, assistance users have also expressed concerns about not being able to express their sexuality in the desired way (Bahner 2012, 2013). Hence, it is a delicate matter for the managers – but nonetheless necessary to deal with in order for such situations to be handled adequately.

The example may also be seen in light of sexual norms labelling certain sexual relationships as more harmful than others – for example, young (non-disabled) women helping older (disabled) men. Not hiring young women can therefore also be a strategy to avoid further 'chaos' (Rubin 1984). On the other hand, the strategy may also serve to strengthen stereotypes against certain types of service users and avoid addressing the source of the problem – namely, why some men act the way they do. From another perspective, the managers' reactions are logical in light of their earlier discussion of what makes a 'good' personal assistant: maturity and experience, which young assistants with no or little former work experience lack.

The gender binary is evident as well, highlighting personal assistance services as a feminine arena, as well as an arena for workers who have little power over their working conditions (Guldvik, Christensen, and Larsson 2014). In other words, the power balance between service user and personal assistant concerns not only the private/professional framework, but also issues of gender, sexuality and disability. In a structural perspective, female personal assistants have low positions on the labour market, but on the other hand, disabled people have low positions in society overall due to physical and social barriers. Including sexuality, an area fraught with individual moral complexity, further complicates issues of sexual facilitation, as shown in previous research (Bahner 2013).

Risk management

Some participants viewed situations concerning sexuality as work environmental issues, resulting in different strategies of managing this 'risk'. One vignette dealt with a service user who was planning a night out with the possibility of meeting a potential sexual partner. In principle, none of the participants were against letting the assistant accompany the service user to a club or similar venue but as they began discussing the case in more detail, the risks became more and more apparent to them:

C3: It's really difficult; you have no idea where they're headed.
C1: No, exactly.

C3: It can also be a work environmental issue.

[Both other participants agree.]

C3: So it's hard. You [the assistant] can end up somewhere where you can't deal with the situation at all, so (mm) I would've probably looked at it work environmentally (mm): can we deal with this or not? What are the risks? (Yes.)

[Both other participants agree.]

C1: Because it's not about us wanting to deny the service user to … a sexual situation (no) but it has to be under OK circumstances …
C3: Yes, we can't get into risks (no) … if there's a risk then …
C1: We have to back away.
C3: We have a work environmental responsibility (mm), it's not … we have to give the employee security (mm). Can't send them, like … no, I would've probably said no (mm).

This discussion ended with one of the managers saying no, examplifying the domino theory of sexual peril and sex negativity (Rubin 1984). A participant in group B said that if the assistant were to assist in a sexual situation in a third party's home, it could also become an issue of ergonomics. Compared to the earlier discussion in which the assistants were seen as vulnerable, in this discussion, it was the service users who were seen as such. Depending on the context, the vulnerable subject alternated, a factor often highlighted in personal assistance research (Egard 2010; Giertz 2012).

When discussing another vignette in which a service user requests assistance with surfing pornographic websites, a similar structure in the discussion developed in group C. One participant started discussing how the personal assistant may be exposed to imagery that s/he is uncomfortable with and that it must therefore be possible for them to refuse giving such assistance – a statement that another participant agreed with. Opposing this, the third participant said that assistants should be prepared to execute tasks that they sometimes feel are not in line with their personal values, because otherwise it would become difficult to manage the services properly if assistants are 'too easily violated'. The other two participants withheld their positions and said that they had work environmental responsibility and that in a worst-case scenario, this could end in sick leave for the assistant, which one of the participants had experienced. Participants in group B thought of even worse scenarios, for example, porn sites containing paedophilia. Another participant said that 'usual porn sites' were ok but 'nothing extraordinary'.

Discussing the worst possible case scenario seemed to be the managers' approach (see also Manthorpe et al. 1997). Hence, the risk of something going wrong weighed heavier than the 'risk' of something turning out in a positive manner, since the managers' professional reputation may be on the line. The taboo surrounding sexuality in general, and in relation to disability in particular, combined with lack of policy support, as well as with managers' discretion, may be contributing factors. Essentially, the discussion concerns what constitutes normal sexuality, and hence, acceptable pornography. Rubin (1984) has described this in her model of the hierarchy of sexual values, where pornography is one aspect that is considered unfitting for 'normal' sexual practice. There also seem to be firm boundaries around what can be considered 'normal' sexuality; that is, not only in terms of what is acceptable according to the law (e.g. paedophilia), but also in terms of moral boundaries.

Creative strategies – insecure positions?

One of the main findings of this study is the multitude of ways in which the managers handled sexual facilitation, and primarily that few of them chose to actively organize it. One reason is that national

disability policies and laws do not mention sexual facilitation, leading to insecurity over whether or not it is even covered by personal assistance services to begin with. Thus, depending on how the managers experienced their own willingness to discuss sexual facilitation, they chose to handle it differently, resulting in different prerequisites for dealing with upcoming situations for personal assistants and service users in different organisations (Bahner 2012, 2013). It also highlights managers' power advantage following their professional discretion (Lipsky 2010).

The managers who did organize sexual facilitation often had an individualistic approach, which can be understood as a privatization of sexuality (Weeks 2010). However, modern society has increasingly institutionalized partnership, parenthood, sexual violence and other 'private' sexual aspects of human life within public policy, leading to a breach of the public/private divide. Nevertheless, several groups of citizens are left behind in these developments, among them disabled people (Shildrick 2007). Sexual facilitation in personal assistance services seems to break new ground in the discussion of sexuality as private versus public. However, the current state makes clear Mollow and McRuers's (2012) suggestion that fear is a common reaction for professionals when encountering these issues.

This framing of sexuality as separate from the professional sphere is one of the factors influencing the managers' understanding of the boundaries around sexual facilitation. Without previously having discussed the issues to any greater extent, all three focus groups agreed that sexual facilitation should only involve the surrounding aspects of sexual acts, for example, preparations before the service user's sexual engagement that they are then supposed to handle on their own. That all groups arrived at the same conclusion in this regard shows the influence of societal discourse regarding 'normal sexuality' (Rubin 1984), excluding not only disabled people as sexual to a large extent, but also sexuality performed with the help of these kinds of professionals. It is therefore not hard to understand why existing material on sexual facilitation is undiscovered. On the other hand, managers' agreement may also be a consequence of using focus groups, as participants with competing views may not dare to contest the majority view that is in line with a strong discourse (Smithson 2000). Individual follow-up interviews with participating managers as well as an inclusion of more managers in the research may therefore be useful in future studies on the topic.

This agreement about the boundaries between 'basic' and 'other' needs, and the placing of sexual needs in the 'other' category, also shows the status of sexuality as distinctly different from other human needs – at least for disabled service users from professionals' perspective (Wilkerson 2011). Siebers (2012) argues that there is in fact no way to avoid sexuality altogether, because even the way professionals act 'professionally' will have 'sexual side effects' for service users (see also Bahner 2012, 2013). Separating sexuality from service users' lives is therefore impossible and human service organisation should therefore acknowledge the need to develop adequate working environments for it. Shuttleworth (2012) proposes including sexuality as an access issue, thereby placing it on the political agenda and as something that is equally important as access to the built environment, education and work.

However, this presupposes strong lobbying from service user organisations as well as political will to change a strong normative framework. Currently, this seems far from realistic when sexual issues are redefined as work environmental hazards, for both service users and personal assistants depending on the context. Managers said that before being able to organize sexual facilitation, they would have to prepare for risky situations that might occur, using administrative procedures. However, few of them had actually done any such planning. Their arguments that they thereby respect service users' privacy and integrity, which is fundamental according to the LSS law, is therefore questionable based on a difference in how professionals and service users understand such concepts (Andersen, Hugemark, and Richter Bjelke 2014). Including managers from cooperative providers could therefore benefit in broadening this perspective, as they often have more focus on service user empowerment.

An understanding of managers' hesitation and insecurity in dealing with sexual facilitation must therefore include perspectives on psychological, social, organisational as well as on societal levels (Kafer 2013). Essentially, this is part of a larger issue concerning disabled people's position in society with regard to everything from cultural imagery to accessibility (Wilkerson 2011). Against

the background of historical repression, independent living through personal assistance services is a great breakthrough. However, as this research demonstrates, services are designed to fit certain organisational frameworks – with less regard to service users' sexual needs than necessary (Bahner 2012). Furthermore, social policy and legislation that include sexuality might make managers less insecure as to how to organize sexual facilitation in practice. On the other hand, Shildrick (2007) cautions against the possible increase in governmentality following such developments and instead proposes a cultural change in views on sexual normality that includes disabled bodies.

But the question is if a cultural change is possible without a simultaneous development in state policy. The absence of sexuality in disability policy shows that there is indeed unequal treatment of disabled people as a group in the name of bureaucracy, professionalism and service user integrity. This is not to say that these aspects are unimportant, but in light of the previously mentioned service user handbook (Svensk 2011), there is apparently both will and initiative to seriously working out these issues in a way that considers the ethical aspects for both service users and personal assistants – as is done in for example Denmark (Kulick and Rydström 2015). Instead of dwelling on a risk-centred approach, a more constructive development could take place in which personal assistants' concerns are further explored, including aspects of for instance gender (Bahner 2013). Against the background of previous research, it is safe to say that silence and unwillingness to deal with these complex issues are not helpful in moving forwards. However, in an era of financial austerity where disability services are increasingly being questioned on the basis of assumptions that service users' rights are becoming too extensive, sexual politics of disability may not be prioritized. The question that remains is therefore, what will it take for this issue to be placed high on the agenda?

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Note

1. These documents have been analysed in Bahner (2015).

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