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”I don’t want a sexualized workplace!”

Personal assistance services and sexuality issues

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Abstract

Title: "I don't want a sexualized workplace!" – Personal assistance services and sexuality issues

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Aim. The aim of this paper is to explore the role of personal assistants in the life of disabled people in relation to sexuality issues.

Background. In spite of the importance of sexuality to the psychosocial welfare of every human being, disabled people are often excluded from being viewed as sexual beings. Research shows that acknowledging these issues is of grave importance for their well-being but that professions dealing with disabled people are often not educated in these issues.

Method. Literature and research is reviewed from the aspect of disability and sexuality. A semi structured interview is conducted with a personal assistant.

Findings. The paper begins with a description of disability politics and its development in Sweden with regards to sexuality issues. Theories on sexuality and disability show that these issues are very much dependent upon current social context, attitudes in society, taboos and values. Disability can therefore be seen as social constructions according to the social model of disability and sexuality as affected by sexual scripts. This is something that was confirmed in the interview with the personal assistant, who also confirms the view of personal assistant services being a low status job, employing uneducated people that often lack the insight of sexuality issues in disability even though they are an extensive part of the care taker's daily life.

Conclusions. Social constructions and sexual scripts in society are hard to change. The sexuality of disabled people is still rather taboo and absent in discussions on higher levels. On websites for disabled people these issues are being discussed and cared for, and therefore we can conclude that there is a discrepancy between the actuality of these issues and how the situation for disabled people regarding sexuality in their everyday life is in fact. Personal assistants need education to be able to handle these things properly and more research in social work must be done to get insight and develop good methods.

Introduction

Although there are no longer laws allowing people with disabilities to be sterilized, there is still what could be called a social sterilization process taking place. Many people with disabilities often get feelings of isolation, exclusion and being met with prejudices. These feelings are often based in a common understanding of people with disabilities being “abnormal” (Lindqvist 2007, p. 45). This is even more often the case when we are discussing sexuality issues, and people with disabilities are frequently regarded primarily as disabled and secondarily as the individuals that they are. People with disabilities are seldom regarded as sexual beings but as asexual (Grönvik 2008, p. 48). The social model of disability stresses the structures in society as determining whether a person is disabled or not, in a social sense. As the society is not accessible for people with disabilities in many physical or psychological ways, it keeps them excluded because of these structures rather than their disability per se (Lindqvist 2007, p. 52, Holme 2008, p. 31). The focus in this study is whether personal assistance services are upholding these structures or disarming them, from the viewpoint of sexuality issues.

Purpose

The purpose of this study is to examine the conditions of the work of personal assistants with regards to sexuality issues and how this affects the disabled person:

How is the personal assistant equipped in terms of competence in sexuality issues with regards to their work?

Background

Historically, the sexuality of disabled people attracted most attention when it was to be controlled. In 1934 Sweden got its first sterilization law. It was aimed at people with different types of disabilities (or deformations as they were called) and sterilization could be decided by the medical doctor without the consent of the person intended. It was believed that these personal defects could be passed on to their children and other people through sexual encounters (because they were also thought to be unable to control themselves sexually) (Engwall 2004, p. 72). Today we no longer have these laws but other structures in society still interfere with the sexuality of disabled people. For example sexuality education in school has been revised to also fit disabled pupils. But this education is taught from a heterosexual

perspective, lacking the HBTQ¹ perspective. A study shows that when revising the sex education for blind pupils, fears of the education not being heterosexual enough were expressed from the teachers. This often stems from a view of disabled people being asexual, and if they against all odds do have a sexuality it is assumed to be heterosexual (Grönvik 2008, p. 47f). Accessibility studies has shown that few of the meeting spots in the HBT community are accessible for people in wheelchairs and that many clubs have doormen with disparaging attitudes. The following citation is an illustration of this:

I have been to gay clubs wearing an obviously gay t-shirt, a pink triangle or some gay symbol like that, and the doorman has asked me if I know this is a gay club and I want to go in still. The assumption is that because I am disabled I cannot be gay. (ibid, p. 56)

But what happens when not a stranger but your own personal assistant treats you with prejudice about your sexuality?

Around 50 % of all people with some kind of a physical disability are in need of daily personal assistance (SOU 2001:56, p. 152). The so-called Handicap Reform in the 1990's emerged as a way to individualize the services and make them possible to choose and shape for the individual rather than be decided on by the professional. The laws of assistance to disabled people that came out of this, LSS (1993:387) and LASS (1993:389), gave whole new possibilities for these people to lead a "good" life, unlike the "reasonable" life other groups in society are to lead according to the law of social services, SOL (2001:453) (Lindqvist 2007, p. 21ff). But the question is if this is possible when we are talking about privacy and sexuality?

The politics of disability are today very much characterized by the national policy plan of action "From patient to citizen – a national plan of action for disability politics". The goals are full participation and equality in society for disabled people. Core issues are accessibility and treatment. This has been described as an important shift of perspective on disabled peoples' position in society. Disability is no longer an individual issue but a societal issue (Holme 2008, p. 33f). The plan of action is to be completed 2010, which is also the Year of Accessibility.

¹Homosexual, Bisexual, Transgender and Queer.

To become a personal assistant no special qualifications are required. The work in itself is not based on any empirical evidence or evaluation and is therefore not subject to formalized routines or professional administration. It is the care taker who decides on work description and method, which makes every case very individual. This may lead to more or less problematic working conditions and environments (ibid, p. 136).

Reports have also shown that a lot of parents of disabled people are pitching in as an informal complement to assistant services or sometimes even as employed assistant (Whitaker 2008, p. 128). This is an acknowledged limitation in privacy and integrity for both the disabled person and their parents (ibid, p. 140). It is not hard to imagine that the sexual identity creating process and sexual exploration can be limited when having personal assistant present at all times or very often, and maybe even harder when it is ones parents.

Method

The method used in this study is within the framework of qualitative research. Firstly, a literature review was made in terms of disability and sexuality with regards to both the person with disability and the professional working with this person (often a personal assistant or a nurse). Secondly, a semi-structured interview was held with a personal assistant, from now on referred to as PA, according to her wishes to remain anonymous. The interview was taped and then transcribed.

The focus in the study has been on physical disability, but since PA had experience from different kinds of disability, those aspects may be mentioned as well.

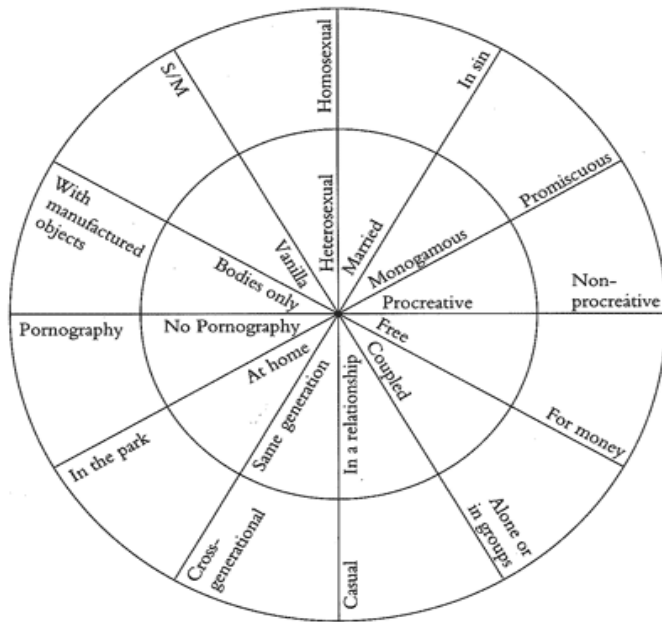
The Swedish word *brukare* does not have a proper translation, why *care taker* will be used to describe the person getting daily care from personal assistance services.

Findings

Theoretical perspectives on disability and sexuality

There are two theories about sexuality being a social construction that can be used in this study; the theory about sexual scripts by Simon and Gagnon (1984) and Rubin's theory on sex hierarchy (1984). With sexual scripts Simon and Gagnon mean all of the templates that

surround the field of sexuality, for example how, when, why and with whom it is all right to have sexual practice. As an example one could take the typical template: a man and a woman, who are in a relationship, in love, having sex in the bedroom at night time, in the “missionary” (Simon & Gagnon 1984, p. 31f). Rubin has a similar explanation, formed as a circle with one inner and one outer circle, where the inner part shows the accepted templates of sexuality and the outer shows the abnormal or bad ones:



(Rubin 1984, p. 160)

As we can see the scripts are very narrow and it is not hard understanding why disabled people’s sexuality is ignored or looked down on according to these theories.

The medical model of disability is outdated when discussing issues concerning the disabled. Today, the social model of disability is more adequate in explaining the factors affecting disabled people in their daily life, factors that have little to do with their disability per se. It is not the disabled people that have to be modified to fit into society, which was the goal of former institutions and such, but the structures in society that have to change to fit the human variation. Disability is something all of us can contract during the course of a lifetime. It varies from situations, cultures and other social contexts whether a person is disabled or not (Lindqvist 2007, p. 56ff). Therefore when talking about disability *and* sexuality, religion, morals and taboos are great affecting factors as well.

Although Sweden is called one of the most equal countries in the world, the templates for sexuality are still very rigid and do not include disability. While non-disabled women are tired

of being regarded as sexual objects, disabled women are tired of being regarded as asexual. Every human being is born with physiological and biological expressions and abilities to lust, love, excite and orgasm but how to act this out is where society puts up limitations (Helmius 2004, p. 103-6). As Helmius puts it “whenever two individuals are together sexually the society is present as a third party” (ibid p. 107). This can also be related to a perspective on disability that has to do with the fact that disability is such a vast part of a disabled person’s identity and life that has been shaped for a long time, which is impossible to think away when talking about issues related to disability (Holme 2008, p. 47). Therefore non-disabled people can never fully understand a disabled person’s life and terms of living.

Research on disability and sexuality

Two different studies by Earle show the need for professional development in sexuality issues when dealing with disabled people. The first study examines the understanding of sexuality among disabled people and their personal assistants. The study shows a discrepancy between how the disabled and the assistants define sexuality, the former as a sexual *need* and the latter as a sexual *want*, including views of asexuality and limited potential for sexual activity. This leads to the sexual needs of the disabled people not being met properly and Earle concludes that these issues must be “discussed and negotiated, in a frank and open manner” between the disabled and the assistant for the possibility to develop appropriate strategies (Earle 1999).

The second study by Earle examines the role of the nurse in rehabilitation of disabled people, which is lacking in attention in sexuality issues. The nurses are said to be working from a holistic care approach, which means acknowledging all factors of a care taker’s body and health, both physical and psychological, but there is a lack of addressing the care takers’ sexuality. Not acknowledging the sexual identity of a disabled care taker may lead to upholding existing power relations in society where the sexuality of the disabled is often denied. Since sexuality is of great significance to individual self-identity and psychosocial welfare this neglect may have far-reaching consequences (Earle 2001).

Many different studies have examined different disabilities and life quality after sickness, amputation and other disabilities. They all show different perspectives of the rehabilitation and the personnel’s competence being insufficient in addressing sexuality issues. Therefore, life quality with regards to sexuality and relationships is lower because of lower sexual self-esteem, sexual satisfaction and sexual activity (Geertzen 2008, Simpson et al 2006, Tamam et

al 2008, McCabe et al 2003, Moin et al 2009). Programs that aimed to improve the competence in sexuality issues among personnel working with disabled people showed great results, as consequences in both values and knowledge increased, which affected the care takers in positive ways (Simpson et al 2006).

Interview with a personal assistant, PA

PA has worked as a personal assistant for more than five years. She has had around 50 different care takers over the years, both men and women, young and old, well-functioning and dying. She has worked in two different cities and within both private and municipal sectors. PA describes her duties as a personal assistant as varying depending on the care taker but the bottom line being helping in the everyday life, i.e. household tasks such as washing and cleaning and helping the care taker with personal hygiene or whatever he or she finds necessary. PA mentions that it used to be called “being the care taker’s hands and feet” but that the expression is not to be used anymore upon request by the care takers, the reason remaining unknown. This is a typical description of what the market and the duties for personal assistants look like (Lindqvist 2007, p. 150). It can be very hard choosing between the different types of services provided and also finding the appropriate types of people who you can trust as your assistant who is able to understand your needs (Whitaker 2008, p. 141).

Other questions remaining unanswered are the lack of supervision and competence development. PA tells about one workplace where they for the first time in her experience finally got supervision, but the supervisor being a colleague from the company and the boss also participating in the sessions, that mainly consisted of them telling the personal assistants how bad they did their job. Regarding courses available for competence development they mainly deal with practical issues such as lifting techniques, CPR, specific conditions (cerebral pares, epilepsy etc) and one about how to handle the issue of working in another person’s home. PA has never attended any of these courses. Her present care taker has advised against it:

PA: The woman, who I am working with at the moment, thinks that the offered courses are too bad so she doesn’t think I should attend them. They call from the office requesting me to attend, but she says that then she has to attend with me to be able to explain how she wants things, in case they teach something that doesn’t comply with the way she wants things.

PA misses courses about ethics, treatment and how to deal with situations where your values and morals are put on stake. For example she has come home to a care taker whose home was filled with pornography and another care taker asking intimate questions. “PA: Of course, everybody should be allowed to express their sexuality, especially in their home, but I don’t want a sexualized work place!”. How does one deal with that as a professional but without having any profession to rely on? The discrepancy between moral values and job description is a common problem for many personal assistants (Lindqvist 2007, p. 154). It can also be seen related to sexual scripts and hierarchies, where pornography is often looked down on as something filthy.

To work as a personal assistance no qualifications are required. Therefore, PA feels very over-qualified working with household duties when she has several years of social science and sexology courses behind her. “PA: I mean, if it’s something I know how to do, it’s being a personal assistant”. Especially working as a substitute can be very educational, since one is being called in for duty to a new person all the time. PA says that the hard thing to learn is how to handle different people and being in their homes helping them with intimate things. This is something she received no instructions on but had to learn the hard way; working in many different places for a long time. But PA also tells that not everybody is fit for this kind of work, you have to be a people person. She has met several personal assistants that were very unfit and who she even gotten fired when it became too bad. But this is something that can only be done if you are a full-time employee; otherwise you have nothing to object about since as a substitute you are rather interchangeable. There are a lot of people standing in line to get these jobs, so if even a minor problem occurs, you can be exchanged for a new person waiting in line. This is probably one of the main reasons for the lack of continuity, loyalty and effort when working as a substitute. This fits the general description of the working situation of a personal assistant (Lindqvist 2007, p. 150). The status of the job has gotten lower, the salary is low and it has developed into a “run-through-job” for many young and uneducated (Whitaker 2008, p. 141).

So the purpose of the Handicap Reform to reduce bureaucracy and professional power relations towards the clients has in fact led to another, unintended consequence. The scope for content has become far too wide and impossible to control and supervise from legal security points of view (ibid, p. 142-5). These issues are actually recognized in different reports, but nothing has actually happened or changed since (ibid, p. 155f). This may also

have to do with a fact that a study by Hugemark and Roman (2007) shows that was made on the Swedish disability movement. They showed that there is a great diversity and division among and within the disability movement in Sweden which makes it harder to make unified claims of social justice and welfare as a group (Hugemark & Roman 2007, p. 26).

As for the courses in social sciences and sexology, PA feels she had more use for her experiences from personal assisting than the opposite; she could use real-life situations as examples when reading about ethics and ethical treatment. It was during the course in sexology that she found out there was a part of it dealing with disability and sexuality, which was more useful as it is very present in the job. She wishes she had had something like that before she started working, because she kind of got thrown into difficult situations already from the start. She tells about her first duty, which was somewhat shocking for her. She and a colleague arrived to a man's home, who they were supposed to give physiotherapy. The care taker was lying naked in bed. But as she soon learned, this was a regular form of duty and nudity was something very normal and uncomplicated. Of course, she got used to it as well, but in the beginning it was pretty hard and she wishes she could have at least talked to her colleagues, since supervision was out of the question.

Something she soon learned was that a good relationship between her and the care taker is the cornerstone for handling difficult situations in a good way. Of course, this is difficult to accomplish as a substitute. Then you just have to trust your instincts and do what you find the most ethical and appropriate in the current situation. A good thing is that the care takers are often more relaxed about these things, since they meet a lot of different personnel and it is part of their daily life to be taken care of in intimate ways. But PA tells of situations where the care takers have used this to their advantage, for example masturbating in her presence or asking intimate questions. Another time she arrived to a care taker whose home was filled with pornographic material everywhere.

I consider myself being pretty relaxed about nudity and sex but [in this situation] I thought it was just too much everywhere and there he was [the care taker], quite a young guy sitting next to me, a pretty young girl, and it just got... weird. At the same time I realize he has got all rights to his needs but I don't feel that I have an obligation to be in a room like that.

But when it has come to care takers with very serious disabilities PA did not experience any trouble with sexual dilemmas. Even if these care takers manifested interests in sexual topics it did not turn into anything that she understood as sexual. PA thinks that this has to do with them being asexualized when they have such serious disabilities. This is something that is reflected in theories and research on disability and sexuality. Persons with disabilities are seldom regarded as sexual beings, and if they are, it is sometimes connected with hypersexuality, fetishisms or sexual perpetrators (especially some specific disabilities have become associated with specific ‘conditions’) (Grönvik 2008, p. 53). PA tells that the one care taker she is working with at the moment is the first one in her experience that has had a sexual relationship and/or activity. None of her former care takers gave any indications on this and she did not think it was of interest and/or importance since they were very ill or very disabled (immobile). Although some of them had partners and maybe assistance around the clock, it was never an issue or a topic to talk about. We can here see how sexual scripts can make it hard even to *talk* about sexuality.

But both research and theories show that most people do have sexual lust, excitement or longing for some kind of a sexual relationship or activity. The problem is that the sexual scripts do not include disabled people and hence their needs and wants are ignored, maybe not deliberately, as PA says, but it is just not something to take into consideration (Helmius 2004, p. 106f). She herself could not think of performing facilitated sex or even be in the same house while sexual activity is taking place:

Even if I am with the care taker in their daily life I want to keep my private... I mean I do not want a sexualized work place even if it is my job. I want them to do their things when I have left. At the same time I realize that it is impossible for most of them because they need assistance, but I do not want to be where I can hear or see something and I would not want to help either. I just could not take it but if others are willing to help that is of course ok. But of course I could go out, maybe take the baby for a walk for example.

PA also tells about how surprised she was when she met her present care taker, who is living together with a partner and has children. Motherhood is a typical social role that disabled women are excluded from and not expected to assume, therefore they sometimes accept it as a fact. But studies on disabled mothers have shown that they are often as fit as anybody else to be mothers, although maybe with some extra help from social services or the family network (Barron 2004, p. 31). Studies have also been made on disabled fathers, who are often regarded

as the secondary parent next to the mothers and not being valued as an important part of the family. When family support is offered to these families, professionals are often directing these at the mother (Sigurjónsdóttir 2004) Again we can see how sexual scripts are showing us that motherhood and fatherhood is for non-disabled people and that these values are materializing in encounters with professionals.

Many parents and/or relatives to disabled people have chosen to take part in the assistance services. They describe it as a dilemma, since having employees as assistants is a great freedom and relief from often heavy care-giving but at the same time you have to get used to living with a stranger in your home (Whitaker 2008, p. 140).

PA has experienced in many ways how there is a great focus on the care takers' rights and nothing on the personal assistants', for good and for bad of course, because on the one hand, disabled people gained a lot of rights but on the other hand personal assistants got almost none. This may have something to do with the fact that disabled people finally managed to reclaim their identities and rights due to the Handicap Reform, and might be willing to step on others sometimes to stay in their newly won position. During the past decades a theory about a *disability culture* has become evident. One talks about disabled people as a specific cultural group with mutual experiences from institutions and being excluded from the majority, a socialization process towards others' definition of normality (Lindqvist 2007, p. 55, Hugemark & Roman 2007).

When talking about the future for personal assistant services PA thinks that it all must radically change, the laws, the rights of the care taker and of the assistant and how they look at one another. PA thinks it is a very good service but it is not working out very well as it is organized right now. When comparing to the so-called home services for the elderly, there is a great difference although it is a very similar job and goal in the services.

For example where I am working at the moment, the care taker has got a lot of hours for washing and cleaning, I do this maybe four times a week apart from all the other things I am doing, whilst the elderly get help at a total of maybe three hours a week! It is totally unreasonable and unethical from a welfare economics perspective. I see a difference between how the elderly and the disabled are treating their assistants, the elderly are trying to raise their status and are very kind, offering coffee and so on, while the disabled are almost

pushing them down to raise themselves, showing that they are in charge. There is also a danger in there being a lot of money involved, it has become a business and there are even bounty hunters trying to find disabled people in need of assistance!

This is a discussion that can be found in the gay movement as well. As shown before, disabled people can have a hard time being accepted in the gay community. This exclusion may seem odd since gay people were considered sick or disabled for a long time. The gay movement aimed to obstruct their exclusion but on the same time they themselves excluded some groups. There is a theory that tries to explain this phenomenon, and it is that in the gay peoples' fight to get accepted by the majority in society they could not take the heterogeneity within the group. That is why there is still a specific image of "a gay person" (Grönvik, 2008, s. 56ff). The same thing could be applied to the disabled people, trying to be accepted by the majority. As a care taker you are in charge for once, which is probably not too common in other situations in your life as a disabled person in a society mainly designed for non-disabled people. Another fitting theory is the one from Apphia, who calls this phenomenon *false consciousness* which means that there are certain processes within us that prevent us from admitting facts that would threaten our position or our privileges (Mulinari, 2006, s. 104). This could be the case with personal assistant services not being good enough, from the assistant's perspective, as they are pretty good from the viewpoint of the disabled person. Unfortunately I do not think that the sexuality issues apparent are enough for the disabled people to complain about, since they have good services in general. As the sexuality of disabled people is still a taboo in society it would also be a harder issue to force into the open.

Discussion

Discussing sexual issues in relation to disability is not a simple thing. Both sexuality and disability can be seen as social constructions and therefore dependent upon social context, attitudes, values and norms in the society and among the people involved. Although sexuality is something that is considered a normal part of a person's life, it is still not the case for disabled people, even though they can many times have a harder time getting privacy and/or functional possibilities for sexual activities. A lot of research has been done from the medical perspective but not so much in social work from social perspectives and everyday life experiences. Having personal assistants or parents around most parts of the day takes away a

lot of possibilities for intimacy with a partner and physical disability can also make it more difficult to act on your sexual feelings immediately and without help. The education of personal assistants in ethics and sexuality issues is therefore of great importance. Parents' involvement in this could also be of necessity. Furthermore, these courses should be broadened and developed together with the care takers in order to get the focus and facts right.

There are some web sites where the disability and sexuality is discussed, for example www.uniquegeneration.se, www.funktionshinder.se, www.sof.se and www.fhobit.se. These sites are open for everyone who is interested, but mainly for disabled people to discuss sexuality issues in forums and so forth. The subject is therefore something rather important but not discussed in the open enough. A start could be to discuss these issues in social work programs and such, where people are studying and in some way surely will come in contact with these issues in the future.

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