

DISABILITY, SEXUALITY AND SOCIOSEXUAL RELATIONSHIPS IN WOMEN'S EVERYDAY LIFE

By Gisela Helmius

Abstract: This article draws on a qualitative study in Sweden in which 21 women from three generations, with congenital physical disabilities, were interviewed about their daily life. Using a social constructionist perspective on both disability and sexuality, this paper focuses on sexuality and sociosexual relationships as part of these women's everyday life. Data indicate that disabled women in younger generations might accumulate experiences of sexuality differently from women in older generations. But regardless of generation, the most common pattern is that these women recount their teenage years as an unhappy period in terms of exclusion from sociosexual relationships. One conclusion drawn is that issues of autonomy, independence and personal assistants in these women's everyday life are brought to a head when they are related to private sexual life. Also, there is still a way to go as regards integration and enabling interventions in the field of women, disability and sexuality.

Introduction

This paper draws on data from a qualitative study of the everyday life of disabled women from three generations, and highlights sexuality and sociosexual relationships. The study had an explorative character and aimed at highlighting the lives of women with congenital disabilities in terms of a lifespan perspective.¹

Data utilized consist of transcribed interviews with 21 women on their collected life experience. In this perspective the interviews do not project a "real reality". Instead, they provide a version of reality that the women have chosen to share at the time of the interview. The selective use of

the material allows the illustration of each woman's situation as she retrospectively perceives it throughout various periods of her life.

In feminist scholarly literature it's argued that concepts and methods for studying women's situation must be taken from studies of the everyday life of women (see Smith, 1987) and Munford (1995) states.

"...that the experiences of women with disabilities must be understood in the context of factors such as their economic positions, their culture and ethnicity, their sexuality, their

geographical locations and lifestyle opportunities." (p 29).

While work, job-market and education are important areas of interest in literature and research on women and disabilities, another area of interest can be labelled sexuality in its broadest sense (Helmius, 1993). This includes sexuality's culturally-based aspects, such as how, when, where, why, and with whom. It also touches upon attitudes towards the body, what is considered beautiful, and women as potential wives, mothers, and lovers. On the one hand, the needs and rights of disabled women to be treated and recognized as sexual beings and potential mothers have been emphasized, on the other hand the vulnerability of these women and the risk that they could be taken advantage of and sexually abused has been foregrounded. (See Deegan & Brooks, 1985; Browne, Connors & Stern, 1985; Saxton & Howe, 1987; Fine & Asch, 1988; Öien, 1988; Senn, 1989; Lonsdale, 1990). Sexuality as an aspect of everyday life is, however, a neglected theme in research on women and disabilities.

The study

Within the frames of the research project "Women, disability and everyday life" conducted 1995-1997 at the Department of Sociology at Uppsala University, Sweden, 21 women from three generations, born

mobility disabled were interviewed about their daily life.²

Qualitative methods were used with in-depth interviews that took on the form of informal talks. The focus was not on disabilities as such. Some women chose to start the interview by discussing their inability to function "normally", other women by talking about their current life situation, and others by relating to the most important events in their lives. The interviews lasted from one to just over three hours and usually took place in the women's homes. An interview guide was used to ensure that certain aspects of their lives were included in all the interviews.

The interviews were taped with permission of the participants and were transcribed in their entirety. Only minor stylistic editing was done that did not change the content of the interviews. The citations selected in this paper have been translated from Swedish into English. Rather than to translate word by word, the striving has been to keep the meaning of the personal accounts intact.

Using snowball sampling, a conscious effort was made to ensure that participants came from a wide range of backgrounds. Interviewees included single and married women, cohabiting women, women active in disability organisations, women outside these organisations, women with children and women without, women with careers and women working in the home, women employed in private businesses and the service sectors,

women from rural areas, women who grew up in institutions and women who did not. Even if the disability was highly visible in all these women, a sliding scale from serious to relatively mild disability was represented.

The overall aim of the project was to examine gender and disabilities in their social context. The choice of methods was inspired by the social constructionist perspective and the relativism associated with the disability concept.

Congenital and acquired disabilities

Bibliographic data indicate that physical disabilities are the most common model used in research and literature on women and disabilities (Helmius, 1993). Moreover, using congenital disabilities provides a consistency of material.

Biographically, there is a considerable difference between disabilities that are congenital and those that are acquired. Women who acquire their disability know what it is like to live as a woman without a disability. For these women the disability disrupts the non-disabled role and self-image that each of them was primarily socialized into. In a study among disabled women in gynecologic health care, women disabled after menarche were less satisfied with counselling about issues such as contraception and sexuality than those disabled before menarche or born disabled (Beckman, Gittler, Barzansky & Beckman, 1989). Thus the age when

the disability occurs plays a role in how the women experience it and the consequences for their own self-image and daily life. (Odgers, 1989).

Based on her own experience and research, Susan Wendell (1996) maintains that a woman who acquires a disability as an adult is placed in a situation in which she must redefine her whole life and reorganize her entire existence in relation to having a different physical condition. It takes time to understand that the primary problem is not the adjustment to the injury or disability, but rather that her day to day life must be restructured to accommodate her new condition. To come to this realisation is a long process requiring time, says Wendell.

This type of adjustment problem does not exist for women with congenital disabilities. A girl born with a disability is treated as disabled by her surrounding and socialized primarily in terms of the disability. But she is also primarily socialized as a disabled child rather than as a girl with an impairment (Lewin, 1987).

The generation model in the Swedish context

The generation model allows the capture of changes in the socialisation process in different time periods, with similarities and differences, and shedding of light on the manifestations and reinterpretations of prevailing attitudes to women and disability. The women studied all grew up in Sweden, but

during the times of different disability policies.

The oldest generation grew up during a period when both the general social-political "safety net" and, more specifically, services for the disabled were non-existent in Swedish society. At this time disabled persons had no legal right to education. If they did receive any education, it was either at the regular school without any special support or at institutions/boarding schools. The education provided at the latter was explicitly vocational in nature and the schooling was based on the limited labour market open to women at the time.

The post-war middle generation grew up as the Swedish welfare state was beginning to form. The increased affluencing and expanding social welfare system helped form these women's lives. They belong to the generation of women who were the first to gain entrance to the labour market.

The youngest generation is the first generation of disabled women in Sweden who early in life enjoyed the benefits of specific political programmes and reforms for the disabled. They have not been forced to go to special institutions for education and vocational training. This generation of disabled women had the legal right to education which was often integrated into the regular classes.

Eight women aged 57-73 years from the oldest generation, seven women aged 37-53 years from the

middle generation, and six women aged 18-33 years from the youngest generation were interviewed. Most of them reside in mid-Sweden.

Sexuality as a social construct

Sexuality as a social construct follows the same social constructionist tradition that views disability and the disability concept as culturally determined. From that point of departure, sexuality is developed in the interaction between the individual and society, and in accordance with current gender systems. Human beings are born with the same basic ability of experiencing sexual lust and drives. Physiological mechanisms such as lubrication, erection, and orgasm are present in the body at birth, but their importance and the value connected with the physical reactions are determined by the culture and surroundings. The individual learns through the socialisation process to view her or his own culturally constructed sexuality as the "normal" and often as the "natural" sexuality (Gagnon & Simon, 1973).

In this perspective, the sexual perspective becomes clear for the individual during adolescence. A person becomes conscious of the differences between sexual and non-sexual behaviors, actions and situations. Young people's thoughts are continually centred on sex. How sexuality *feels* is a central question for young people. Sexuality is private and establishing one's own sex life can be a

step in becoming independent from parents, in creating one's own self-image and identity. An individual becomes *someone*, at least in the eyes of the person who offers love to that person (Lewin & Helmius, 1983; Helmius, 1990).

The circumstances surrounding this type of identity development appear to be different for women and men. Sexual norms and morals are and probably have always been more restrictive for girls and women than for boys and men. Girls have been "protected" from the dangers of sexuality through problem oriented sexual education instead of being encouraged to learn about themselves as sexual beings and see their sexuality as an opportunity and a resource.

Protection and alternatives

The literature and public opinion often discuss the relationship between disabled children and adolescents and their parents in terms of overprotection (See e.g. Barron, 1997a, pp 85-92). This means that parents attempt to create a protected setting when caring for their child that stops the child from taking her own initiative and learning to care for herself and her daily needs. By fear young women may be trapped in their parental homes (Hendey & Pascall, 1998). And by fear they may be subject to a sexually disabling socialisation process (Lewin, 1987). Mary³ from the oldest generation in the study, states in the interview:

"But it was always like that. They would keep certain things from me since I wouldn't be able to do it myself. That way I wouldn't risk failing."

Overprotection and the prevailing restrictive sexual morality for girls combine to make adolescence a problematic development phase for women born disabled. At the same time as the child is in need of different forms of help and the parents are the most natural providers, the child is expected to liberate herself from her parents and create a life on her own. Sonja, from the youngest generation, provides a retrospective picture of the complexity in a disabled young woman's liberation process:

"It was like this. My best friend was a year older than me and she had a boyfriend when she was 18 years old and I was 17. Then suddenly she moved away from home because her parents didn't accept her boyfriend. Then I started nagging at my mother all the time. I was a rebellious teenager but the only thing I could do was nag. I couldn't run away from home and I couldn't run out and be out all night, and, you know, I had to use the transport service and I was checked all the time and so on. I mean, that's how it was. The only thing I could do was stamp my feet and leave the room in my

wheelchair or roller and slam the door behind me. You know how it is. I can see it so clearly now. I was very rebellious. But it was really a matter of needing practical help. You know, washing my hair, taking a shower, help getting dressed, help tying my shoes, making breakfast, you know, everything you can normally do as a child and teenager, you know. I needed help with all those things. So I started protesting against it all."

As Karin Barron (1997a) in her research on adolescents with physical impairments asserts, the meanings of independence and autonomy do not primarily refer to the individual being capable of doing certain things such as cleaning and cooking in her own household, or taking care of her personal hygiene. The main point of the terms is instead that the person can exert influence in her everyday life and that she is supplied with the resources to make her own choices.

This study supports the idea that issues of autonomy and independence in the field of women and disability are brought to a head when they are related to sexuality and individual private sexual life.

Stina, from the youngest generation, tells about her and her husband's situation:

"Steve is an extensor spastic and I'm a flexor spastic, and this

creates some practical difficulties. My body's quite stiff and I guess we aren't imaginative enough to get it right. It would be pretty embarrassing to need to request assistance in a situation like that."

Womanhood and sociosexual relationships

In her interview, Maya in the oldest generation tells that she married when she was about 20 years old, had two children, and divorced when she was in her 50's. At 67 she says with a laugh, "Sexuality has passed me by without me noticing it." Sonja, in the youngest generation, relates her sexuality however to prevailing norms of marriage and companionship:

"I think that I am normal. I got married when I was 22. There's nothing odd with that. People have always done that. Either you've been a little younger or a little older, but it's normal. Or it's the same with managing on my own, that's a part of being normal and having a relationship is proof that you're normal or anything like that."

The concept that sexual normality exists risks making women with impairments sexually disabled. It narrows the opportunities for the women to experiment sexually, with or without access to a personal assistant. Women who grow up with a disability

risk getting caught in a desexualizing socialisation process to a greater degree than women who acquire a disability as adults (Macdougall & Morin, 1979; Lewin, 1987). Their interaction with their surroundings are colored by social attitudes to both disability and sexuality. It is not a given fact that disabled girls and boys are included in the same sexual socialisation process as their peers without disabilities. Therapy, habilitation and rehabilitation deal with mainly practical things such as prostheses and how to use a wheelchair. Time is spent training and visiting the hospital and physical therapist. Sexuality is pushed into the background or the vague future. The literature points to deficiencies in sexual education for adolescents growing up with a physical disability, and studies show that students who have grown up sensory-impaired have less of an understanding of sexuality than non-disabled students (see Welbourne, Lifschitz, Hanan & Green, 1983; Baugh 1984; Stevens, Steele, Jutai, Kalnins, Bortolussi & Biggar, 1996).

Differences as an asset

One aspect of disabled women's everyday life that is only slightly touched upon in the literature can be noticed in the interviews. This is the disability as an asset in a society created for non-disabled persons, which, as Sally recounts, can be used to satisfy a personal curiosity towards sexuality.

Sally, from the youngest generation in the study, is severely disabled. She grew up in a dysfunctional family and did not receive much encouragement from her family:

"That time with my mother in the countryside when I was 13, I asked her what it was like to sleep with someone. She just said it wasn't anything for me to think about."

As part of her attempt to break away from her parents, Sally chose not to attend the integrated school. Instead, she moved to the state boarding school for disabled adolescents.

"But it wasn't to study. I wanted to have fun and have a good time. I could decide when I wanted to go to bed, and no one was watching over me. Sure there were rules, but I didn't pay much attention to them. And I drank incredible amounts. It's amazing I didn't die. Maybe my teenage revolt was much more exaggerated."

In the freedom she achieved by living in an institution, Sally used her disability to make contact with potential partners among non-disabled boys and men:

"I know what I did. I've always used my disability. You need help

with this or that or can you move that or can you help me go over there or to the restroom, or not, those kind of things, maybe help me over to the bed, or, so that they would be placed in that position so that something could happen. I used that all the time, if I think back on it, it was pretty fun because I really thought about it and planned it. It was actually pretty smart. I made sure I used that which others saw as negative or somehow incapable."

At the time of the interview, Sally is married and has two children. Contrary to Maya in the oldest generation, sex has always been a dynamic dimension of Sally's life. She describes the first time she had sex this way:

"Well, I was curious. Luckily, I had a fellow who I had met and he was also very curious. I was lucky when I think about it that it was with him since he was, how do you say, interested in making it good for me. And I don't think that's very common among guys. He wasn't very experienced, but he had a lot of imagination. And that was good for me. Cause if you're both shy and disabled, then it's not easy to take the initiative, physically I mean. So you have to say what you want. If I remember right from the first

time we were together, I didn't dare to even cough once, so I remember it wasn't very easy. But the first time didn't go so well, but after that it went better. Sex was actually the only thing that worked for us. Otherwise we didn't get along so well at all."

Sally's way of describing her first time, her approach to how she gets sexual experiences, and her own role in this learning process, are hardly marked by a view of sexuality as an expression for romantic love or a view of women as passive objects. It is more instrumental in nature in a way that is traditionally reserved for describing how men view sex. She transcends the constraints of traditional gender roles in terms of sexuality and sociosexual relationships.

Sally grew up in a home where she had not been encouraged to develop as a sexual being and with a severe disability that defined her in many respects. In spite of this, she found security in her state of being different. She rarely felt scared or vulnerable in sexual relationships with men although she would not have been able to extract herself from a situation without the help of others. The strength she felt in being different, unique in her own and her partners' eyes, and being forced to verbalize her wishes provided her with security and authority in sexual partnerships. At the same time, she was frightened and insecure when she had to rely on her mother's help on

a daily basis or when she had to be out in town after dark.

Looking back at their youth

The older the women are at the time of the interview, the more experience they have to compare with and relate to. The oldest ones have been able to reinterpret and reanalyze experiences from their youth during different phases of their lives, while the youngest ones more recently have left their teens. But regardless of generation, a common theme in the interviews is the experience of the teenage years as a difficult, unhappy, and trying period, not unlike a personal tragedy. It is portrayed in this manner by a number of interviewees. Malin from the oldest generation declares:

"Never again a teenager! If I was able to relive my life, I don't think I'd want to relive my teenage years again."

And Lisa from the middle generation says:

"It was bad when I was a teenager and in my twenties. Everyone else started working and getting boyfriends and moving away from home. And me? Poor little me? It was a difficult time."

While Sofia from the youngest generation recounts her teenage experiences in the following way:

"-Did you ever ask someone out on a date? -Yes, but I got rejected. They said that they liked me a lot, but the problem is that the boys look at each other and they can't go out with someone who is handicapped."

The interviews indicate that the women were treated by their peers as siblings and friends while growing up, even if under difficult conditions. "...I've had siblings to deal with" (Laila). "I was with the boys and climbed in the trees and used my bow and arrow" (Malin). "That's when I started to get teased, but I also had learned to give as good as I got" (Mary). They were active in a contact network where sexuality and disability were secondary attributes and of minor importance. Long hospital stays and time-consuming habilitation programmes could at times change the character of their daily lives, but they did not threaten the girls' group affiliation. Mary in the oldest generation spent long periods at the hospital for surgical procedures, but her group of friends was always there:

"Yes, they could get a whack if they weren't nice. But you see, I grew up in a little neighbourhood. There was a big gang all about the same age. There were seven or eight of us born in 1937 or 38 and we stayed together all the time."

Lisa reflects over how little she understood about her own disability growing up:

"I still haven't quite understood. I haven't seen myself as a traditional disabled person if there is any such thing. When I lived at home I had my sister who was two years older than me and she took me everywhere. Wherever she was, I was. Basically I haven't had a group of friends who are disabled. I haven't felt very different from others, not as much as perhaps I should have."

But during adolescence, childhood friends risk splitting:

"I was a scout and we were out every spring and there wasn't anyone there who took any notice of something being wrong. That's how it was. But then of course my friends starting going out and dancing. That's what you did when you were around 16. Then, then I wasn't with them any more, that's when I started being in the scouts instead cause that was better for me than going out and dancing. /"Didn't you want to go out?"/ No, no. Oh, no. I don't think so, no I didn't. I wanted to, I assumed that I'd just be a wallflower that no one would want to dance with and I'd just sit there all night. I didn't

want that. I was probably mainly scared. I've noticed lately as I've gotten older that when things like that have happened, I've usually run away. I'm not scared of things in general, but in this case I have been. I'd rather just leave." (Molly).

Adolescence is perhaps the most critical period of a person's developmental process. In addition to a biologically based inner restlessness, the girl or boy also has to deal with an outer social insecurity. The young person is supposed to break away from her parents, find her identity, and incorporate sexuality into her personality. Results from studies concerning this developmental phase, from the clinical and psychological perspectives (Lagerheim, 1990) as well as within the social sciences (Jarkman, 1996), show that during this period young disabled women come to understand that they actually are "different" physically from their peers. Their own impairment becomes evident for them and they are weighed down by yet another aspect to deal with on what Barron (1997b) has called "the bumpy road to womanhood".

Disability, sexuality and socialisation

Culture determines sexuality's social acceptance in terms of when, where, how, why, and with whom and adolescent sexual socialisation involves learning to attach social meanings to private sexual activities. In the light of

social constructionist theory, including the view on disability and sexuality as culturally determined, disabled women in younger generations might have accumulated experiences of sexuality differently from women in older generations. Society changes, as do attitudes towards disability, sexuality and gender, and the studied women's internalization of sexuality into everyday life has taken place in different societal contexts.

Historically sexuality has been tied to reproduction, with reproduction socially accepted within marriage. Maya and Malin in the oldest generation grew up when women according to prevailing norms depended on marriage and men for their living. But women born mobility disabled were hardly attractive on the local marriage market. Maya and Malin transcended traditional gender roles when their disability became the driving force for acquiring an education and a career. Later, marriage and motherhood did not prevent them from giving priority to their work outside the home. In her interview, Maya says with a laugh that she never paid much attention to sexuality.

Linda in the middle generation grew up in an institution where girls and boys had few opportunities to meet in private. There she became acquainted with a boy, and when they were engaged to be married they left the institution to live in a flat of their own:

"It was like heaven! I had my own key. For the first time in my life. Could do my own cooking. I made many mistakes, but it was freedom. Unbelievable!"

Empowered by her relationship and her position as a married woman and a traditional housewife, she gradually became curious about her sexuality and her powers to attract men in a societal context adapted to non-disabled persons. Some years later she married a non-disabled man:

"He was passion, when everything was carried to extremes. And he made me live. With him I recognized that sex is a great pleasure. That I could function."

In the interviews from the youngest generation, sexuality is handled as an unequivocal aspect of women's lives in general, most often in terms of relationships, marriage and motherhood. These women grew up with sex education, counselling and contraceptives easily available and with a permissive view on adolescent sexuality. Unfortunately, because sexual morality has always been more restrictive when it comes to girls and women than boys and men, girls growing up are not supplied with encouragement, support and possibilities from the adult society to get to know sexuality as a resource and themselves as sexual beings. Non-disabled

adolescents are however able to spontaneously and in step with individual maturation incorporate sensuality and sexuality into everyday life. In interaction with peers they learn what adults do *not* teach them about sexuality. To the best of their ability they put into practice internalized sociosexual norms and ideas together with peers who are in the same situation and in the same stage of sociosexual development (See e.g. Helmius, 1990).

But a person born blind cannot determine at a glance if a "where" is socially acceptable and a person whose body does not look like "everyone else's" is not obviously the right "with whom" (Helmius, 1991). Incorporating sexuality into one's own everyday life is not a self-evident possibility for a young woman who is not able to move around on her own or without attracting unwanted attention.

Conclusion

Sexuality has been an important part of the feminist agenda. At the same time disabled women's situation has been overlooked both in the women's movement and the development of feminist theory (See Morris, 1991; Begum, 1992; Wendell, 1996; Kallianes & Rubinfeld, 1997; Segal, 1998). Kallianes and Rubinfeld (1997) also argue that neither women's movement nor the disability rights movement has given enough attention to issues such as sexuality, mothering

and reproductive freedom from the perspective of disabled women.

This article has aimed at shedding light on sexuality and sociosexual relationships as part of disabled women's everyday life. In conclusion, three characteristics should be pointed out.

First, the women studied regardless of generation most often recount their teenage years as a difficult, an unhappy, and a trying period in terms of exclusion from sociosexual relationships. Second, there is a greater awareness of sexuality as an unequivocal aspect of disabled women's lives among the women in the youngest generation than those in the oldest. Third, issues of autonomy, independence and personal assistance in disabled women's everyday life are brought to a head when they are related to sexuality and private sexual life.

Certain circumstances can help some succeed in making sexuality and a sexual dimension part of private life, despite all odds and with considerable effort on the part of the individual. As a teenager one woman in the youngest generation consciously used the severe disability to satisfy her curiosity about her own sexuality, and she felt self assertiveness and security in the fact that the disability made her unique for her sexual partners. Yet, there is still a way to go as regards integration and enabling interventions in the field of women, disability and sexuality.

Notes:

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² For a more detailed account see Helmius 1999.

³ All names in the interviews are fictitious.

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