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Falling in love with a wheelchair: enabling/disabling technologies

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Abstract

The aim of this article was to explore how young women with physical impairments make use of technology in their identity construction, drawing on the metaphor of the cyborg as well as on science and technology studies and disability research. In addition to participant observation, semi-structural interviews were conducted and video diaries were kept of the women playing sledge hockey, wheelchair basketball, or table tennis. The informants included their wheelchairs in constructing their identities as young women and active subjects. In talking about pleasure and strength, they opposed the discourse that characterizes disabled people as leading empty, tragic lives. They challenge stereotypical notions of gender in sport by displaying determination, strength and risk-taking, while embodying a more traditional femininity when resisting the widespread view of disabled women as non-gendered and asexual.

Introduction

This article was the result of a research project on how young female athletes with physical impairments relate to their own bodies and to the field of sport. The aim was to explore the meaning of technology in the women's lives. The research questions posed were: how did the interviewees avail themselves of the social, cultural and political values that are linked to technology? How did they use technology in the construction of their identity?

Method

Participant observation was made at a disability sports camp for young people with physical or intellectual impairments (or both), and at four disability sports contests – one national and three international – to get an understanding of the local jargon, local routines and power structures and by that get a feeling of what the interviewees will talk about. Ten semi-structural interviews were done with young women ranging in age from 15 to 27 years, in addition to informal interviews with leaders, coaches and volunteers. In trying to grasp the experience of disability from the point of view of the young women studied, video diaries were used. The latter have the potential to capture processes, body language and facial expressions. A small camcorder and a lightweight tripod were lent to some of the informants. Three video diaries were made. While the interviews dealt with the informants' relation to physical activity, their body and their physical capacity, the scope of the video diaries were
broad. The informants were asked to videotape their daily lives, as though they were going
to show them to a stranger.

The informants were recruited from both the sports camp and disability sports clubs.
They played sledge hockey, wheelchair basketball, table tennis and rode on horseback. In
Sweden, team sports for disabled people differ from team sports for able-bodied people. Since
female teams are rare, women must play in mixed teams, where they are in the minority.
Therefore, both team and individual sports were included in the study.

The term ‘impairment’ is used here with regard to physical dysfunctions, and ‘disability’
when referring to restrictions imposed on a person by the society. However, this distinction
does not imply a binary division between the biological and the social, in which the body is
regarded as pure nature or pre-social. From a social constructionist perspective, a more
complex understanding of impairment and disability is needed. Sociologists Bill Hughes and
Kevin Paterson claim that ‘Impairment (as physicality) cannot escape either cultural meanings
and beliefs or its embeddedness in social structure. On the other hand, oppression and
prejudice, not only belong to the political body, but become embodied as pain and
“suffering”.’² Thus, impairments can be understood as socially interpreted and social
restrictions are embodied.

Disability sports in Sweden
The physician Ludwig Guttmann, of the Spinal Injuries Centre at Stoke Mandeville Hospital
in Aylesbury, England, is a central figure in the history of competitive disability sports,
although there have been other agents and earlier competitions.³ In 1944, Guttmann
introduced a programme of sports as rehabilitation and recreation for soldiers and civilians
who had been injured in the war – most of them in wheelchairs as a result of amputations or
spinal cord injuries. The first Stoke Mandeville Games took place in 1948 and became an
annual event. The first international competition was held in 1952, a forerunner to the
Paralympics. Guttmann regarded them as therapeutic, providing physical as well as
psychological and social rehabilitation. The identity of participants as disabled people was
underlined: ‘It was their disabilities that created a sports world specifically for them –
separate, spatially and symbolically, from the “real” world of sport outside.’⁴ Thus, a
medicalized view characterized the emergence of disability sports. This was supported by a
classification system based on impairment or diagnosis that was intended to ensure fair
competition. Nowadays the system of classification has changed and is based on functionality
instead.
The development of the Swedish disability sports movement can be seen as part of the building of ‘folkhemmet’, the people’s home. The preparatory work during the 1950s and 1960s was inspired by the ideas of Guttman. The Swedish Sports Organization for the Disabled [Svenska Handikappidrottsförbundet, (SHIF)] was founded in 1969 and is today one of 70 specialized sports federations within the Swedish Sport Confederation [Riksidrottsförbundet, (RF)].

Contemporary Swedish disability sports differ considerably from the rest of the Swedish sports’ movement. Swedish sports are both a product and an effect of the social democratic hegemony that considered it a vehicle for social inclusion and equality. It is organized as a ‘folkrörelse’, or popular movement, supported by volunteer work and public financing, and including children’s, recreational and professional sports. Sports sociologist Tomas Peterson claims that the Swedish sports movement balances two tasks: cultivating democracy and encouraging competition. Democratic forms of social intercourse are grounded in respect and equal rights for all, regardless of gender, class, religion, or ethnicity. For the society, the most important role of sport is training good citizens and providing meaningful activities for children and youth. Competition is also inherent in the logic of sport, involving performance, selection, ranking and elitism. In the RF programme, physical, psychological, social and cultural development on all levels is described as the main goal, alongside of promoting democracy and striving for gender equality:

On all levels we want to carry on our sport in order to positively develop people both physically and mentally, as well as socially and culturally. An important part of the sports movement’s democratic fostering is that every member, given their age and other qualifications, can have an influence through being responsible for themselves and their group, through meetings that are democratically structured, as well as through everyday training and competition. This is especially true of children and youth, who in this manner receive early training in the basic rules of democracy through sports clubs. All planning of sports activities should be carried out with a conscious gender equality perspective.

However, these somewhat contradictory aims do not characterize all parts of the Swedish sports’ movement. The original aim of disability sport was, as cited earlier, neither democracy nor competition. The SHIF ‘Disability Sports Policy Programme’ does not mention competition or democracy at all. Instead, rehabilitation and social integration are presented as its main goals, together with an eye towards lowered public expenditures. As the introduction to the programme states:
There is hardly any other activity operating so effectively for the rehabilitation and social integration of disabled people as disability sports. It has added benefits for society in the form of reduced costs for care and social welfare.\textsuperscript{12}

Furthermore, the programme characterizes disabled people as weak:

It is no overstatement to say that disabled people have a pressing need to improve their physical status, in order to master assistive technologies that are necessary for mobility. Wheelchairs, crutches, etc., require strength that must be acquired. Training solely for the movement of one’s own body is the first prerequisite for having a tolerable existence.\textsuperscript{13}

This alleged inherent weakness should be valid for all the different groups of people with impairments that SHIF organizes: those with physical, visual and intellectual impairments. Similarly, the assumption seems to be that such individuals only have a ‘tolerable existence’ if they receive training. It appears that by not teaching children and youth about the democratic process and the possibility that they may someday make positive contributions to society, SHIF constructs disabled people as passive clients of the Swedish welfare state, instead of capable, active citizens. In describing such individuals as weak, in need of social integration, and a burden on public finances, SHIF contributes to a negative discourse of considering disabled people pitiful, needy unfortunates.\textsuperscript{14} As in the Stoke Mandeville Games, the impaired body – the one that deviates from the norm – is the central focus. A medicalized view of disability sports is also to be found in the media, both in Sweden and internationally. The diagnosis (in the case of a congenital impairment) or the accident (in instances of acquired impairment), as well as the subsequent rehabilitation, are the concern, rather than sporting achievements.\textsuperscript{15} However, as the Swedish pedagogue Kim Wickman points out, when disabled athletes are interviewed and quoted by Swedish sports media, the published accounts do concentrate on their performance.\textsuperscript{16}

**Theoretical reflections**

*Medicalization and normalization*

There are significant consequences of the above-described medical discourse for disabled people. Philosopher and historian of ideas Michel Foucault, writing of how power is exercised over bodies, states that through ‘a continuum of apparatuses (medical, administrative and so on)’ bio-power, a term he coins, disciplines individuals and regulates the population by means
of control and correction. ‘Such a power has to qualify, measure, appraise and hierarchize . . .
A normalising society is the historical outcome of a technology of power centred on life.’
Thus, within medical discourse, or more specifically, the rehabilitation discourse, the ‘disabled body’ is produced and regulated. Medical professionals have the power to determine which bodies are legitimate and which are in need of correction and normalization. A body is evaluated and, depending on the results of the assessment, the amount of home care, technical and financial support from the welfare state is decided. In this way medical and social professionals exert control over the lives of disabled people, thereby undermining their autonomy and creating dependency. The assessment of the body is based on an idea of the ‘normal’ way one should look, be and act, and as a result disabled people are constructed as abnormal and deviant. ‘In this way, normalization, and its technologies, contribute to the reproduction of the differences and asymmetries that they seek to escape and undo.’ Hence, the compensatory strategy of the welfare state creates and perpetuates boundaries between able and disabled, normal and deviant.

Wickman claims that sports technology, like prosthesis, may challenge those boundaries by reducing physical differences and contributing ‘to the production of “super sportsmen” and “super sportswomen”’. But no matter how good sports achievements may be, the impaired body is still regarded ‘as different and considered inferior to the nonimpaired body’.

The metaphor of the cyborg
The role of technology is largely unexplored within disability studies, perhaps because researchers now reject earlier medical models of explanation that were based on normalization, and have replaced them with social and cultural analyses of disability. One possible way of analysing the function of assistive technology is suggested in A Cyborg Manifesto: Science, Technology, and Socialist–Feminism in the Late Twentieth Century, by feminist and historian of science Donna Haraway. She uses the metaphor of the cyborg as a rhetorical feminist strategy and utopian vision, which she describes as ‘an act of taking over a territory’. Haraway’s cyborg is a hybrid of an organism and a machine, as well as a synthesis of social reality and fiction. Whereas Foucault makes the normalization process visible, the cyborg – a female figure on the fringe – illuminates and questions the normal. Rather than an essentialist and universalistic feminism, Haraway, who references postcolonial feminists, advocates coalitions based on solidarity instead of identity. Working in coalitions or through networks implies ‘the permeability of boundaries in the personal body and in the body politics’, pointing out their heterogeneity. Haraway claims that we all are cyborgs who
use information technology and modern medicine but, she adds, ‘Perhaps paraplegics and other severely handicapped people can (and sometimes do) have the most intense experiences of complex hybridisation with other communication devices.’

Haraway only mentions disability once in *A Cyborg Manifesto*, and cyborg theory has mostly engaged disability metaphorically. But Ingunn Moser, a science and technology researcher, applies Haraway’s notion of the cyborg as an alternative to prevailing rehabilitation discourse and as a possible figure in theorizing about a marginalized position – that of the disabled. The cyborg allows her to explore new subjectivities that have been made possible by the use of computerized technology. Moser writes about Alf, a man who lost his faculty of speech after a stroke and became partially paralyzed on his right side. By means of computerized technology Alf maintains contact with the world around him and with his life before the stroke. The computer gives Alf a voice and makes self-representation possible. In this way he becomes an agent instead of a passive recipient, and restores his dignity. The computer has become ‘a friend, an ally. But it is also an intimate part of him’. Moser argues that Alf’s subjectivity comes into being in the relation between body and machine, that is, through the heterogeneous cyborg.

Haraway discusses the cyborg metaphor in relation to late twentieth century’s information technologies. These machines blur the boundaries between the natural, conscious human being and the artificial, non-conscious machine, a notion Moser refers to in her empirical study on the use of computerized technology. The concept of the cyborg may be fruitful in examining the idea of a natural, whole, normal body in relation to people who use wheelchairs and sports equipment. While Moser does not discuss gendered aspects of Alf’s usage of technology in self-representation, the present study explores how interviewees made use of and challenged the gender discourse of technology and sport. Haraway maintains that the metaphor of the cyborg blurs the dichotomies nature/culture, body/machine, active/passive, and controllable/uncontrollable. The empirical material used in this discussion adds the polar opposites able-bodied/disabled, and normal/deviant within the medical or rehabilitation discourse, as well as those of male and female.

‘Othering’ and resistance

The wheelchair is often regarded as a sign of difference. Ingela, who is 19 years old, claims that the students in her first school wished to exclude her as one of their classmates:
I was the only one sitting in a wheelchair. And then, they didn’t really want to . . . They stood in front of me and said, ‘Oh, she pushed me’ and sort of ‘ran into me’ and such things. So you see, they didn’t want me at all. I was pretty much alone.

The wheelchair was a hindrance in the interaction between Ingela and her classmates, both literally and metaphorically. Two more interviewees talk about how able-bodied people focused on their wheelchair. Nathalie and Malin, both 15, recalled strangers in town asking them questions about why they used a wheelchair. While this does not bother Malin, Nathalie explains it is ‘a bit tiresome. I don’t want to answer people who I hardly know.’ Nathalie also speaks of how people stare at her in situations when she is the only one using a wheelchair: ‘When I am going horseback riding, for instance. Then someone has to put me up on the horse because I can’t get up by myself. Then people may be staring ... It’s really annoying!’

Sociologist Bill Hughes discusses the importance of the ‘non-disabled gaze’ in the Othering of disabled people. ‘The non-disabled gaze is disfiguring yet it assumes itself to be an act that identifies disfigurement.’ According to Hughes, the classification done by the non-disabled gaze when sorting out the bad and the ugly is not neutral, but constitutes a moral and aesthetic discourse. He connects it with the medicalization of disabled people that reduces them to a diagnosis. The diagnosis confirms the gaze, and the subject becomes annihilated. When Nathalie is set upon the horse, it is not her impairment per se that constitutes the hindrance, but the non-disabled gaze. In each of the three empirical examples above, the wheelchair is central to the Othering of the young women, and in each of them being reduced to a diagnosis.

A striking resistance towards being characterized as disabled, and against the pity that often follows, emerged during the interviews. This resistance is in some cases connected to technology. Maria, 17 years old, showed me her wheelchair and remarked:

This is my favourite wheelchair ever ... It is so tremendously fine! It is really gorgeous! It is so easy to handle, and it is really pretty! ... It is sporty in a pretty way. Otherwise, I don’t use to like the word sporty, but ... It is pretty because it is not the chair you see when you see me. But it’s, so to speak, me. Precisely, just like it should be. Yes, it was love at first sight! There is room for improvement, absolutely, but yes. I’m simply in love [with it].

Maria’s expression of love for her wheelchair is part of a conscious strategy against pity. She calls herself a fighter. Criticizing the treatment she gets from people in everyday interactions, she claims that ‘the worst thing you can do is pity someone’. Her resistance is explicit when
she tells about a teacher in school who asked her to give a talk about ‘difficulties in the everyday life of a disabled person’. The teacher invited Maria to do this in a gesture of open-mindedness, that is, as an expression of the ‘discursive climate of tolerance’. At the same time he was unknowingly subordinating her as problematic and needy. In her talk Maria only spoke of positive experiences to avoid being positioned as a ‘poor cripple’. But her resistance is also implicit. When Maria tells about a vulnerable situation, she risks, as a woman, being seen as a victim. Her disability reinforces the picture of her as passive and helpless – someone to pity. Thus, when confronting me, an unknown, able-bodied interviewer, it seems of great importance to her that she distances herself from the subordinate categories she constantly risks being cast into. Maria manages this skilfully, on the one hand by telling about experiences of discrimination and, on the other by observing her own stories and adding, ‘It wasn’t anything serious. Maybe it was a bit wimpish. It really wasn’t anything [the teacher] said to be mean.’ By talking about her wheelchair as pretty and by claiming it was ‘love at first sight’, Maria opposes the view of it as a sign of difference and personal tragedy.

While Maria fights alone, Hanna and Sara, 25 and 19 years old, respectively, both of whom work as coaches at a sport association, speak forcefully about rights of disabled people. They state that disabled athletes are like everybody else: they are capable human beings, able to speak for themselves and there are no grounds for feeling sorry for them. Sara explains that she becomes irritated when she hears comments like: ‘Oh, you are disabled and you can still do things!’ I hate it when people say things like that, and when they get really impressed just because today, for instance, I can drive a manual car; or they say ‘Oh, even though you have that, you can drive a car!’ Why shouldn’t I?’ Sara claims that because she is disabled, it is presupposed that she is incompetent. Then, when she uses the technology of ‘normal’ people – a car not adapted with accessibility features – the boundary between the deviant and the normal is transcended, and Sara is met with astonishment.

Hanna works for a disability sports club as the leader of a girls group. The reason for starting up the group was the sexism some of the women had encountered in pursuing disability sports, and the fact that women are in the minority. The group strives for equality, tries to raise each member’s consciousness and self-confidence and introduces the young women to various sports. But they are determined to change the view held of disabled people by doing things like contacting media about the invisibility of such people in society. Hanna relates the story of a colleague to explain the importance of raising the level of one’s consciousness and working for enhanced self-confidence:
You never got a chance to speak your mind. She [the colleague] said that ‘When I was younger and they were going to try out a leg prosthesis, no one ever asked me if it was a good fit. They asked my parents if it was good, and they said yes or no’. And that’s the way it has been ever since. Making up one’s mind about the smallest things becomes really difficult.

Hanna says that several of the women in her sports group have had similar experiences in their childhood and adolescence of not being given the opportunity to voice their opinions, although there are exceptions. The group organizes a fashion show with women in wheelchairs as models. In this way those I interviewed are acting as cyborgs, showing resistance – individually and collectively – from an oppositional position in the borderland, and trying to move into new territories.

**Assistive technology and sports equipment**

*Femininity, pleasure and strength*

Ingela has a sledge that she uses for the disability sport of ice sledge hockey. Ice hockey is considered one of the most masculine sports, according to a Swedish survey. The same is probably also true of ice sledge hockey, a seated variant of ice hockey. Ingela’s feeling of not being completely accepted by her classmates changes as soon as she arrives with her sledge:

> When I bring my sledge and my classmates have been skating, then they are sort of like, ‘Wow, I want to try!’ And then they become completely different. And when I am with my older brother . . . they change. It is hard to explain . . . [It is like they are saying] “I am your best friend!” Because they probably wanted to try it . . . Then, the next day, they are just the same as before.

Ingela moved from a position of rejection to acceptance as the owner of a piece of desirable sports equipment. The sledge temporarily gives her the status she otherwise lacks. So does the presence of her older brother, a football player. On the one hand, sports is a field where the boundaries between able-bodied and disabled are strong. Athletes strive for peak performance by training for the perfect body. ‘The idealised, mythic valuing of the perfect body, with its association of personal virtue, carries as its counterpoint the denigration of persons with different bodies. The unspoken assumptions about these bodies, and their inhabitants, relate to undesirability, psychological damage, abjection and failure.’ Inclusion of disabled people would threaten to destabilize the construction of the normal, human body and the boundaries
between the two categories. On the other hand, sports equipment and assistive technology are two fields close to each other. Shoes for different sports, specially-designed canoes and custom bicycles are used for more easier, faster and smoother performance. Assistive technology of different kinds, such as wheelchairs, prostheses and crutches, are also used for the same purposes. While Ingela does not actively and explicitly fight against being categorized as disabled as Maria does, as female sledge hockey players they both challenge the discourse of disability by being active and capable. They also oppose the gender discourse in sport by showing themselves to be young females who play a tough contact sport involving strength, endurance, danger, risk-taking and violence. Technology is of vital importance in this effort.

Maria illustrates the link between sports equipment and assistive technology by characterizing her wheelchair as sporty, thus relocating it from one field to another. She also shifts her wheelchair from a masculine discourse of technology to a feminine discourse of accessories, when talking about it as ‘tremendously fine’, ‘really gorgeous’ and ‘sporty in a pretty way’. Such talk is a way for her to construct femininity despite sitting in a masculinely-coded wheelchair. Ethnologist and gender researcher Denise Malmberg has interviewed women between 50 and 60 years of age who had visible physical impairments. They spoke of fighting against the image of disabled women as non-gendered and asexual, and how they have tried to be accepted as wives, mothers and lovers, counter to the feminist struggle against defining a woman in the above terms. Feminist disability researchers have criticized gender researchers for ignoring these issues and thereby contributing to the oppression of disabled women.

Disability scholar Rosemarie Garland Thomson points out that the cultural image of disabled women disturbs two opposed paradigms. Being seen ‘as the opposite of the masculine figure, but also imagined as the antithesis of the normal woman, the figure of the disabled female is thus ambiguously positioned both inside and outside the category of woman’. Like those in the group that organized a fashion show with young women in wheelchairs as models, Maria counters the image of the disabled woman as non-gendered and asexual in the way she talks about her wheelchair, thereby constructing a more traditional femininity. Haraway’s cyborg is a female figure who questions the normal. She is what Moser calls a ‘bad girl’ who refuses to be a woman. Those interviewed do not refuse to be women, but they are ‘bad girls’ insofar as they do not accept the ascribed subject position as being non-gendered.
The emotional life of these women extend beyond merely declaring their identity in an able-bodied world. Hanna recounts her sheer delight in physical activity:

I was scheduled for an operation on Tuesday, but we had a training camp scheduled in Stockholm from Friday to Sunday. So it was my last basketball training session, you could say. It was rather fun. I drove like anything that Sunday. And then on Thursday I lay completely flat and couldn’t move.

Hanna contrasts the memory of how she ‘drove like anything’ during the training camp, which gave her pleasure, and how a few days later she lay immobile after having back surgery. When the interview took place, Hanna had not been in training for almost a year because of her operation. Telling me about her capability and skill as a basketball player became important for her self-representation, so that it was in accordance with her self-image, and in this self-representation technology played a significant part.

Susanne, 22 years old, eagerly related how she loves driving at high speed in her wheelchair, her dog running at her side, and sweating heavily. ‘It is fun. And it’s high speed. It’s not strolling . . . If you have been out on a really long walk with the dog and you come home, like completely sweaty, you know, it is a marvellous feeling.’ Susanne’s focus on joy and having fun counters a negative discourse of disability, or what Sunderland et al. call ‘missing discourses of joy and happiness in relation to disability’. In Hanna and Susanne’s stories about how bodily feelings of speed, strength and pleasure arise, technology and body are inseparable. As for Alf in Moser’s study, technology is ‘a friend, an ally . . . an intimate part’ of their lives. The boundaries between body and machine dissolve.

**Conclusion**

We have seen the importance of technology to disabled people, both as a sign of difference, and as part of their resistance to being stereotyped by other people. Those interviewed made use of their wheelchairs when constructing their identities as young women and active subjects. In talking about pleasure and strength they oppose themselves to the discourse that sees disabled people as passive, needy and pitiful. They also challenge the gender discourse within sports by displaying toughness, strength and risk-taking, while constructing a more traditional femininity against the view of disabled women as non-gendered and asexual. Like heterogeneous cyborgs, they question the dichotomies between organism and machine,
natural and artificial, able-bodied and disabled, active and passive, normal and deviant, female and male, as well as the idea of the essentialist wholeness of the human body.

Notes

1 Kvale and Torhell, *Den kvalitativa forskningsintervjun*, 92. (All translations by the author)
2 Hughes and Paterson, ‘The Social Model’.
4 Hargreaves, *Heroines of Sport*, 181, italics in original.
9 Ibid., 10.
10 Ibid., 11.
11 Svenska Handikappidrottsförbundet, ‘Handikappidrottspolitiskt program’.
12 Ibid., 3.
13 Ibid., 8.
14 Apelmo, ‘(Dis)Ability and Citizenship ’.
17 Foucault, *The History of Sexuality*, 144.
22 Moser, ‘Disability and the Promises of Technology’, 388.
23 Ibid. 374–5.
26 Haraway, *The Haraway Reader*, 322.
27 ---, *Simians, Cyborgs, and Women*, 170.
28 Ibid., 178.
32 Ibid. 163.
34 Koivula, ‘Gender in Sport’, 54.
35 Schwartz and Watermeyer, ‘Cyborg Anxiety’, 189.
36 Ibid. 188 s
38 Malmberg, ‘Kvinna, kropp och sexualitet’.
References


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