Cultural Perspectives on the Body and Functional Variation: What do bodies do to us and what do we do with our bodies?

Kulturella perspektiv på kropp och funktionsvariation: Vad gör kroppar med oss och vad gör vi med våra kroppar?

Turku, Finland, 8 March 2019

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The seminar "Cultural perspectives on the body and functional variation"[1] was organized by the Society of Swedish Literature in Finland (SLS) in collaboration with the disciplines of Folklore and Ethnology at Åbo Akademi University. Researchers and experts were invited to this seminar to present and discuss different conceptions of normality and body in contemporary society. Although there has been research on functional diversity prior to this, functionally diverse people have often been excluded from the discussion and reduced to objects of study instead of being seen as experts. Furthermore, disability is often highlighted as a problem, ignoring the social and cultural prejudice and discrimination against people with disabilities, which is known as *ableism*. This seminar aimed at expanding the discussion on functional diversity, including a broader variety of viewpoints, and placing it within a societal context. The audience consisted of students, researchers, and other people active within the field and engaged in these questions. The speakers used different terms for functional diversity, but I have chosen to use primarily the perhaps outdated concepts of "able-bodied/disabled" for reasons of consistency and readability.

All presentations were in Swedish. The seminar was opened with an introduction by Ruth Illman, Chair of the Committee for ethnology and folkloristics at SLS. The first presentation was given by Dr. Maria Bäckman, University Lecturer at Stockholm University, and was titled *To not see – but be seen. About exposed bodies and the desire to pass.* Bäckman's areas of interest include questions of meaning-making, gender, sexuality, youth, democratic ideals, multiculturalism, and the creation of difference and similarity. In this project, Bäckman conducts auto-ethnographic research on people who have lost their sight, partly or fully, in adult age. Bäckman herself has had visual impairment for a few years, and she believes that her own experiences give her insight that

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[1] Editor's note: The concept of functional variation (funktionsvariation in Swedish) refers to the diversity of special needs and disabilities. Another English language translation could also be functional diversity.

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ETNOLOGIA FENNICA Vol. 46 (2019), 154–157. https://doi.org/10.23991/ef.v%vi%i.82506

eases and enriches the interview process because she knows what questions to ask. Although focusing on her subjects, she uses her own experiences as a point of departure and pays specific attention to the *cane*. Bäckman argues that there is a duality to the cane. It is a good and easy aid, but simultaneously it signals to the surroundings that the cane holder has visual impairment, which can be a source of shame and resentment. The canes expose their holders as disabled, ruining their chances of passing as a "normal" able-bodied person. This disinclination to be noticed as disabled Bäckman connects to *ableism* and the internalization of social narratives that deem being disabled as something undesirable. Bäckman presents the cane as a social materiality that has the power to change a social situation. Thus, it is not simply a tool, but an extension of the person and the self. What is crucial for cane holders, according to one of Bäckman's subjects, is to start considering the cane as something that enables them, rather than something that disenables them.

Dr. Carolin Ahlvik-Harju, Research Associate in Systematic Theology at Åbo Akademi University, spoke under the title *Liberated or troublesome? About the presence of a different body*. Ableism was also discussed in this presentation, in which Ahlvik-Harju explained how the abled body is presented as "normal" and ideal and the disabled body as deviant and undesired. She noted that disabled bodies are also often presented as a trouble or inconvenience to society, schools, and families. This notion has its roots in history, where negative or difficult aspects of disability have often been highlighted, while the positive aspects and noteworthy disabled people have been erased. Ahlvik-Harju, suggested a three-fold solution to the problem of ableism. Firstly, we should highlight disabled women in history and tell their stories. Secondly, we should examine our culture today. Disabled people get little visibility in popular culture, and when they do, it is often in a sense of "inspiration porn." This means that disabled people are highlighted and admired as a symbol of strength, which ultimately makes them more objects than subjects. Thirdly, Ahlvik-Harju urged people to ponder about the people in their lives. Do people have disabled people in their lives? Do they see them as potential friends? She argues that there is political and moral explosive force in friendship, and being friends with disabled people can not only enrich their lives, but also the lives of the disabled.

Dr. Kristofer Hansson is Docent in Ethnology at Lund University. In his presentation, *The body in the neoliberal city—a functional impairment perspective*, Hansson talked about diverse physical obstacles that exist in society for people with disabilities. Using "go-along" as a research method, he ventured out with people in wheelchairs to find out how they handle themselves in society. He presented some examples of situations that may appear unproblematic, but from the perspective of a person in a wheelchair can become impossible. For example, getting on a bus full of people and the ramp not working, or going around a car parked on the sidewalk where moving from the sidewalk to the road is impossible. These kinds of obstacles can cause disabled people not to go out in society on their own. Hansson discussed ableism, the normative "ideal body," and how quickly people's goodwill can turn to disdain when they start to view disabled persons as "a problem" for them. In conclusion, Hansson argued that the obstacles for disabled people exist in physical, social, medical, and normative cultural ideals, and not in the bodies of the disabled.

Christine Bylund, Doctoral Student in Ethnology at Umeå University, spoke about *Theorizing "one's own"—the possibilities and pitfalls when working with one's own experiences and body as material*. Bylund described the power structure of functionality, which is built on cultural ideas about which bodies are good and desirable. In this context, it is the healthy body. This system recreates itself because it is allowed to determine how knowledge is created and who is allowed access to education; for example, when disability is studied, disabled people are deemed to be solely "knowledge bearers" while the researcher is the "knowledge creator," which is often performed in comparison with the functional, abled body. Being functionally disabled herself and partially using her own experiences in her research, Bylund discussed questions regarding the research field: where it begins and ends, how to be critical of her own functions that do fit the norms, and what kinds of acts of solidarity and perspectives an auto-ethnographical approach allows her. Researchers always need to be aware of their place, and they need to be able to understand and describe it. However, Bylund noted that this can appear more important for functionally disabled researchers when researching disability, because they appear to be "speaking for themselves," even though everyone always speaks for themselves. Conversely, she noted that it could be a pitfall for her if people place unfounded trust in her simply because she is disabled herself and thus do not dare to question her.

Lastly, we heard Hanna Grandell's practical perspectives on the body and functional diversity. Grandell is a member and spokesperson of the association "Steg för Steg" (step by step), which is a Swedish-speaking Finnish association for and with people with mental disabilities. The association works for functionally diverse people to be heard and seen in society. Its members learn about their rights, talk about their experiences, and make decisions on matters that are important to them. Grandell told us about her life with a mental functional diversity and about trying to fit in, not understanding bullying, and thinking the world is a good place until she was forced to understood otherwise. Most shockingly, Gardell told us about how she has a degree but is not allowed to work within that field because of her disability. Instead, she and other people she works with have to do menial full-time work, while not being properly compensated for it. Despite this, Gardell has a very positive outlook on life and does not envy “normal” people, as she feels that they are more restricted by norms and ideas regarding how they are supposed to be.

Questions about whose voice is heard, who is allowed to create knowledge, and who is given a place at the table when decisions are made regarding people with disabilities are increasingly discussed in both public and academic domains. Still, ableism is a less-discussed subject if compared to racism or sexism. In order to create an equal society, it is crucial to understand the experiences and challenges of functionally diverse people, and how they are created within cultural, societal, and historical structures that idealize those who are considered “able-bodied.” As stated, the obstacles for disabled people do not lie in their disability, but in society and the minds of people.

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