

Kenny Fries & Rebecca Maskos

## **Building Bridges. How Swantje Köbsell's Disability Studies work has influenced us**

### **A conversation**

#### **Abstract**

As a bridge builder between ‚the street‘ and academia, Swantje Köbsell is a true networker, connecting actors in both spheres, and thus embodies the essence of Disability Studies, whose central starting point is activism. As an activist of the disability movement and the feminist movement, Swantje Köbsell organized visible and loud protests against an exclusionary society and her work simultaneously reflects the power relations of the non-disabled ‚norm‘ which provokes protest. At least, that's what Kenny Fries and Rebecca Maskos carve out in their conversation. The American writer and the German disability studies researcher and free lance journalist reflect on the influence Swantje Köbsell's work on the cripple's movement and on the critique of bioethics has had on them.

## **Building Bridges. Wie Swantje Köbsells Arbeit in den Disability Studies uns beeinflusst hat**

### **Ein Gespräch**

#### **Zusammenfassung**

Als Brückenbauerin zwischen ‚der Straße‘ und der Wissenschaft ist Swantje Köbsell eine echte Netzwerkerin. Sie verbindet Akteur\*innen beider Sphären und verkörpert damit die Essenz der Disability Studies, deren zentraler Ausgangspunkt der Aktivismus ist. Als Aktivistin der Behindertenbewegung und der feministischen Bewegung organisierte Swantje Köbsell sichtbaren und lautstarken Protest gegen eine ausgrenzende Gesellschaft und reflektiert in ihrer Arbeit zugleich die Machtverhältnisse der ‚nichtbehinderten Norm‘, die diesen Protest auslöst. Zumindest stellen dies Kenny Fries und Rebecca Maskos fest. In ihrem Gespräch reflektieren der amerikanische Schriftsteller und die deutsche Disability-Studies-Forscherin und freie Journalistin, welchen Einfluss Swantje Köbsells Arbeit im Feld der Krüppelbewegung und der Kritik der Bioethik auf sie gehabt hat.

**Rebecca Maskos:** Kenny, it really amazes me that we never really talked about how Swantje brought us together. That's even more surprising as we all seem to take for granted that she brings people together all the time, and thus seems to be doing what Disability Studies is actually about: Intertwining activist action and activist thought. Please tell me again: How did you meet Swantje and what were your first impressions of her?

**Kenny Fries:** I remember well meeting both you and Swantje. In 2013, when I was applying for funding to research in Germany, I was introduced to Swantje by noted U.S. disability rights activist Marilyn Golden, who was my first mentor in all things disabled. Marilyn, who was instrumental in passing the Americans with Disabilities Act (ADA) in 1990, had spent time in Germany consulting with German disability rights activists interested in the law's implementation. Swantje generously agreed to write the invitation letter required by the funder. I received the funding and arrived in Berlin on September 1, 2013.

A few nights after I arrived, Swantje, living in Bremen, came to Berlin. On that night, not only did I meet Swantje in person for the first time, but also Swantje introduced me to you, who I already knew from Riva Lehrer's portrait of you, which I had taught in my classes on cultural representation of disability.

On that night not only did two important friendships begin but I also learned from you and Swantje a bit about how disability is ‚measured‘ in Germany when you both showed me your disability IDs, something we do not have in the U.S. or Canada, that stated you were both 100 % disabled, and according to the “H” designation on your IDs, ‚helpless‘. The irony of being with you and Swantje, two incredibly smart and powerful women, being deemed ‚helpless‘ was, of course, amusing, if somewhat disturbing, to the three of us.

How did you first meet Swantje?

**Rebecca Maskos:** Her name had crossed my path early on. I was still living at home with my parents. My mother, active in the self-help movement of parents of disabled children, had a few used issues of *Die Randschau* at home. At the time, *Die Randschau* was the magazine of the cripple's movement in Germany. I loved to leaf through the issues. The radicalism and outrageousness of the authors made me suspect that somewhere out there, there are ‚other‘, ‚cool‘ disabled people, who roll past the bullies with their heads held high, who give the finger to shame, who analytically pick apart their own social marginalization with the weapons of argument.

The name of the former addressee was still stuck on the covers of *Die Randschau*: Swantje Köbsell. The address: A street in the trendy district of nearby Bremen. Later, in the mid-nineties, I met her ‚live‘ for the first time, at Bremen University. I was a psychology student with an interest in the topic of disability – a field that was completely underexposed in my studies. I took a class in special education, on disabled women. I was suspicious of this, because I thought that only non-disabled people were doing research there, over the heads of people like me. With corresponding skepticism, but nevertheless curious, I went to the first session. Surely a non-disabled woman would want to explain to me the reality of my life.

To my great amazement, the lecturer was a feminist and disabled herself – it was Swantje. I was relieved and impressed. What followed was a class full of ‚eye-opening‘ moments. After that, we kept running into each other in Bremen. After the initial feeling that, as a student 15 years younger than her, she was certainly not taking me very seriously, a friendship and complicity developed.

A few years later, long after I had started to work as an editor at *Die Randschau* magazine myself, I moved into the attic apartment of her house, on the street in Bremen's trendy district, two floors above her. This is a legendary house that Swantje had helped to establish as a coop-house for disabled and non-disabled

people in the early 1980's, one among many Bremen projects on disability that would have not seen the light of day without Swantje's work. Since living under the same roof with her now, I regularly sat with her in her living room, gossiping with her over white wine spritzers, marveling at the first seedlings of German-language disability studies, or discussing the latest steps of bioethical considerations, which once again put the lives of disabled people at stake. I think she was one of the key people that encouraged me to follow the path of Disability Studies in Germany.

**Kenny Fries:** Your story of your Swantje origins shows not only how important she was, and still is, to both the disability rights and feminist movements, but also how it is the action itself that is important to her rather than it being about herself. You bring up bioethics, which reminds me of the course Swantje and I taught together at Alice Salomon Hochschule. One class was about ‚assisted suicide‘. At the time, Swantje's father was ill and she couldn't make it to class, which she was scheduled to lead. Thankfully, she had notes she translated into English so I could lead the class in her absence. Also, the students scheduled to present at this class were usually quite well prepared. They were. But one of the students showed a video about how wonderful it was to choose one's own death, a decidedly non reflective and non contextual ‚propaganda‘ piece by one of the better known Swiss organizations that helps one set up one's own ‚assisted suicide‘.

It was clear that the students didn't know how to use a disability studies perspective to understand the important issue of ‚assisted suicide‘. I was nonplussed and no matter how much I tried I couldn't turn the class discussion into a disability studies critique of the video from Switzerland.

I very much missed Swantje that day. Not only because I thought she could have, in her eloquent way, turned that class around but also because I felt quite alone as the only disabled person present that day. What I liked most about teaching that class with Swantje is that we were two disabled people teaching together, rather than being the ‚only one‘. From what you said, having Swantje as a teacher was important to you because you then had a disabled comrade in the classroom, which is still not so usual in academic institutions.

**Rebecca Maskos:** Absolutely. For Swantje, researching, writing and teaching about disability has always been closely linked to the activism of the disability movement. As a student of special education, she became part of Bremen's *Krüppelgruppe* – Cripples Group. Its members messed with non-disabled power, dissected, analyzed and theorized it. They justified the practice of their at times radical actions very precisely, for example in their texts for the *Krüppelzeitung*, a forerunner of *Die Randschau*.

Non-disabled people were supposed to stay outside and first learn to understand the *cripple's point of view* – today one would say: reflect on their privileges. I remember Swantje telling me about February 18, 1981, when she, together with the *Krüppelgruppe*, had chained herself to the banister of the local parliament's stairs, going on a hunger strike. She and her comrades were protesting against cuts of funding for a driving service for Bremen's disabled citizens, and for public transit accessibility in the city. They had great success. After two days, Bremen's parliament stopped the cuts.

For Swantje, it was always clear that the arrogance and patronization that she and the others had endured during the hunger strike – politicians not wanting to talk to them, rather calling an ambulance, finally giving in because so many cripples in wheelchairs protesting was too painful to watch – that all this was an integral part of the structures that had prompted the protest in the first place.

**Kenny Fries:** It is notable that these radical actions, of which Swantje was an integral part, might make one think of her as unapproachable. But this can't be further from the truth. When one meets, and gets to know, Swantje, she is approachable, by students, by colleagues, by friends. Her openness and willingness to share her experience and expertise is remarkable.

**Rebecca Maskos:** Very true. And it's an openness that is intersectional in its very essence. I think her personal experiences as a disabled woman influenced her activism and scholarship tremendously. What it means to be regarded no longer as the 'pretty young girl', after her spinal cord injury as a young woman, but as the 'poor thing' who had better not have children and at most a job as an underpaid typist in an office – that seemed to have been deeply impressed on her.

Swantje became a feminist early on and felt part of the women's movement. Like many feminists with disabilities, Swantje found that her perspectives were rarely heard there, or even met with rejection. For example, disabled women's critique of the unreflective, eugenicist parts of the feminist struggle for reproductive rights. "Mein Bauch gehört mir" – "my belly is mine," as you could translate the famous slogan of the German pro-choice feminist movement, was a rallying cry that Swantje supported unconditionally. Yet, as she pointed out, the discourse around prenatal diagnosis often negotiates the life value of disabled people. Thus, her early writings also revolve around heteronomy and self-determination of female bodies, and bioethical questioning of the value of disabled people's lives.

Her first book from 1987 criticizes and publicizes the practice of forced sterilizations on women with learning disabilities. Together with Theresia Degener, in 1992 she wrote "Hauptsache, es ist gesund?" ("As Long as the Baby is Healthy?"), the first German book that critically discussed feminist self-determination under human genetic control from the perspective of the disability movement. Later, she also took up end-of-life debates, which you talked about earlier, and euthanasia discourses – also as gateways for the individualization of disability and its equation with permanent, unconditional suffering. Although she is not a historian, she always has Germany's Nazi past in mind and points out its continuities. That is also a common theme of yours, isn't it?

**Kenny Fries:** Yes, it is. I first came to Germany to research the lives of disabled people who grew up in the GDR (and it was Swantje, and you, who told me who I should interview about this). But I soon realized I couldn't understand disability in Germany without going back to the Nazi period, and even earlier. That's how work on my almost finished book, "Stumbling over History: Disability and the Holocaust", began.

Something Swantje wrote in an article for *Disability Studies Quarterly* remains an important tenet in my work:

"For those born after the Third Reich, the postwar trials of Nazi doctors who had been part of the euthanasia program and later campaigns for the legalization of assisted suicide were always a reminder of the consequences of a conception of humankind that declares certain people's lives as 'not worth living.' From the very beginning, disabled peoples' right to life was a major issue for the German Disability Rights Movement. The discussion of eugenics – a legacy from the Third Reich – and later on, bioethics – were central to the Movement" (Köbsell, 2006, o. S.).

Thinking about this, I am reminded of the memory studies idea of multi-directional memory. In my version of multi-directional memory, when looking at a historical event, one doesn't equate what happened with what happened in the past, or the future, but looks at resonance between events from different time periods. In Swantje's article, she emphasizes how an understanding of a movement, in this case the German disability rights movement, needs to be understood as part of a continuum of history, one that looks both backward as well as forward.

**Rebecca Maskos:** People like Swantje are unfortunately still really rare in Germany. When you look to the U.S., how do you feel about this interconnection of theory and activism? What challenges do figures like her face in the future, in the U.S. and globally?

**Kenny Fries:** The big difference I find with Disability Studies in the U.S. with that in Germany is in the U.S. Disability Studies is more rooted in the humanities, in literature and history, for example, whereas in Germany it is more a part of education and social work. I think there are important activist figures in the U.S., such as the late Judy Heumann, who are more in line with Swantje's activist history but unlike Swantje have not been part of academia. So, I think Swantje is rare in bringing her activist perspective into academia. Judy ended up working in government, whereas Swantje ended up being a professor. I know there are others who have taken a similar path in Germany, Theresia Degener for example, but surprisingly, most of the activists I know in the U.S. aren't in academia but in the arts, Alice Wong being a good example of a U.S. activist who is a writer. Also, in the U.S. there is a lot of discussion about how 'white' Disability Studies has been, and now, importantly, the Disability Justice Movement, which centers racialized histories and people is taking Disability Studies to where it needs to go. Swantje's work on disability and migration would fit very well into where Disability Studies is going in the U.S.

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## Literatur

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