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Welcome to the lecture "What is disability?"

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My name is Swantje Köbsell, I am a professor of Disability Studies at the Alice Salomon University of Applied Sciences in Berlin

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and contentwise, this lecture will be about the following: First of all, we want to take a look at what disability actually is,

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in order to then look at the available models of disability and which effects they have for those affected?

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Subsequently, the lecture will discuss disability studies and the significance of ableism, disablism and intersectionality in that context. The lecture will end with a conclusion.

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First of all, the concept: disability. Many people do not know that disability is still a very young concept.

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For a long time, people we now call disabled were referred to according to the nature of their impairment.

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They were the lame, the crippled, the deaf, the blind and so on. It was not until the 1920s that the term slowly gained acceptance and was initially mainly used in the context of physical impairments.

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And it was only with the adoption of the Social Assistance Act (Bundessozialhilfegesetz) in 1961 that it was introduced as an umbrella term for all people with impairments which then led to the term very quickly becoming established in both legal and everyday usage as precisely this umbrella term.

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If we now look at who is labelled with disabled, disability, we have to realise that, unlike gender, for example, we are dealing with a very unstable category when it comes to disability.

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The boundaries between disabled and non-disabled are fluid. It is often not clear who actually belongs to which category. It can also change in the course of history. Certain impairments disappear and new ones appear, for example impairments caused by poliomyelitis no longer exist here, but they do so in other countries. And the human body also changes throughout the course of life.

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This means that anyone can acquire an impairment if only he or she lives long enough.

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In our everyday understanding, disability is the designation of a physical, mental, psychological or sensory deviation from what is considered normal. This is accompanied by stigmatisation, discrimination, you think of suffering, of dependence, of a tragic fate.

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This means that disability has a predominantly negative connotation. And the underlying model is called the individual or medical model because it focuses strongly on medical, deficient diagnoses. It represents the traditional image of disability that is still the dominant one in many social and scientific areas. In this model, disability and impairment are equated, which means that disability is located in the body of the impaired person.

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Disability is a tragic fate and the only thing that can be done in this model is to try to heal. Where this is not possible, to adapt to normality as much as possible or to tell people that they have to accept it and figure out how to get along.

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In this model, disabled people have no rights but are recipients of pity and disability is presented as a social problem. This model sends a very clear message to disabled people, namely: "You are wrong. We have to change you." In this model, disability appears as a static, natural and fateful, supra-temporal and supra-cultural phenomenon.

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This means that disability has always been like this, will always be like this, there is nothing you can do about it and it is like this everywhere.

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This has implications for the people labelled as disabled. In this view, they are considered a helpless, needy, dependent and genderless group that cannot speak for themselves, but also must not speak for themselves. That is why experts are needed to speak for disabled people. This means that this model justified the dominance of disability specialists such as doctors, therapists and educators. The choice of words (in the German original) is deliberately male because when the medical model was particularly dominant, specialists were predominantly male.

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As already mentioned, this means that disabled people are not legal entities but recipients of pity and alms for which gratitude is expected, and as a result their lives are characterised by far-reaching heteronomy.

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There is no political self-advocacy and participation in society is very limited.

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Objecting against this, disabled men and women joined forces in Germany at the end of the 1970s and beginning of the 1980s. In these associations, they began to defend themselves against paternalism, omnipresent exclusion and discrimination.

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They fought for self-advocacy, for self-determination, for social participation.

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And the background for this was a new view on disability that had been developed by disabled people themselves. In Germany, there has never been a really crisp wording, which is why the following quote from the British Union of the Physically Impaired against Segregation is always used in this context, which was formulated as early as 1976: "In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society."

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That means that disability becomes something that is not located in the person, but something that society imposes on people with impairments, thereby preventing them from participating in society. This view is the foundation of a new model of disability called the social model of disability, which, as the UPIAS definition shows, is characterised by the fact that it separates the individual level, impairment, from the societal level, disability. Impairment refers to the physical, sensory, cognitive or psychological deviation from social normative notions and disability thus is the result of social attribution and exclusion processes based on the negative evaluation of this deviation from social normative notions.

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With this view of disability, disability was denaturalised and disability was understood as a social construction. However, if something is a socially constructed, it can be changed. The social model therefore also offered an instrument for analysing the social construction process. The social model can be summarised as follows:

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People are not disabled, but numerous barriers disable them, such as stairs as physical barriers, but also mental barriers such as attitudes, prejudice, discrimination and the like. And the social model emphasises: disability or experiences of disability are not supra-temporal, supra-cultural, but are always related to historical, cultural circumstances and change or can be changed.

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And the social model correspondingly has consequences for the people concerned.

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It triggered a change in self-view. The message is: "It's not me who is wrong, it's the society that excludes me" and that resulted in a struggle for equality and recognition as a citizen.

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Disability is thus transformed from an individual problem into a task for society as a whole, the goal of which should be social change, towards a society of equals, towards inclusion. We can therefore conclude: Models of disability have a decisive influence on the way we deal with those affected and are important because they determine their opportunities to live and participate.

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The new perspective on disability, as already mentioned, now enabled a closer look at the social processes in which disability is produced and this is the background against which international and interdisciplinary Disability Studies emerged.

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They emerged from political disability movements in the USA and the UK in the 1970s, simultaneously but independently of each other. And one could say a lot about this, the developments were of course not one hundred percent the same, but we can say: both in the USA and in Great Britain, Disability Studies are now well anchored in the academic infrastructure. You can study Disability Studies there, pursue a degree in Disability Studies.

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There are regular conferences, publications and specific journals.

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In Germany, on the other hand, there were people from the disability movement who got involved in academic contexts and also very explicitly represented this new view of disability there, but the idea of forming a specific academic structure only developed very late, following the example of disability studies in the Anglophone region, and led to the founding of the working group "Disability Studies in Germany: We do our own research" and for Germany it has to be said that even 20 years after the founding of this working group and 50 years after the start of the disability movement, Disability Studies is hardly anchored in the academic structure.

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There is also no journal yet. But it can be said that there are now a number of institutes, more and more books are being published and the number of conferences on Disability Studies has increased in recent years.

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What do Disability Studies want? They examine constructions of normality and their effects from cultural as well as historical perspectives, and for the historical perspective they have formed its own sub-discipline called Disability History. Ultimately, it is always about processes of constructing disability and non-disability. In which contexts, in which social, cultural and scientific fields is non-/disability produced in which ways?

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What do for example literature, the media, but also jurisprudence and other fields contribute to this construction process? Which role do social institutions play in this process, but also interpersonal interaction in the sense of "doing dis/ability"?

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Engaging in Disability Studies also means a change of perspective in research on disability.

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Instead of doing research on people with impairments, research is now conducted by and with people with disability, who thus become active research subjects and are no longer research objects as they were in traditional disability research.

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It is thus about analysing and revealing discrimination, prejudice and violence, about analysing social practices and discourses in the context of impairment and disability.

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It is about putting people with disabilities at the centre of research, giving them a voice and

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ultimately promoting social participation, self-determination, accessibility, equality and civil rights, and also helping to develop social strategies for this in order to ultimately achieve a society of equals and thus inclusion.

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Central to Disability Studies and increasingly a topic of discussion is the concept of ableism, analogous to other "-isms" such as sexism, racism, classism, this is about "able", hence the Anglicism, it does not translate well into German, and it is about assumptions and practices that justify different and unequal treatment of people based on apparent or assumed differences.

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In an ableist view, certain types of self and body are set as perfect, typical, central to being human, and correspondingly deviating types of self and body are then seen as being less worthy forms of being human and not as another facet of human diversity, such as gender, sexuality or ethnicity. Ableism influences attitudes, ideas, social manners as well as measures and programmes in the context of disability. This means that it ultimately has an impact in all areas of society and is often, or hardly, noticed.

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Ableism is accompanied by what some authors call disablism, which can be described in German as "Behindertenfeindlichkeit", namely that ableism leads to discriminatory, oppressive or offensive behaviour that arises from the belief that people without the abilities considered essential in ableism are inferior to others. Ableism, however, is much more than hostility against disabled people:

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While such hostility really only affects the disabled or those marked as disabled, as different, ableism ultimately affects everyone. As Rebecca Maskos writes, it also affects those who meet or even exceed the norm. The fact that those perceived to be attractive are often also suspected of being extremely nice, clever and charming is essentially just as ableist as the assumption that people of small stature are particularly funny or clownish, or that blind people are naturally musical and have a superb sense of hearing.

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Ableism can reduce all people to their physicality.

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Another approach in Disability Studies that has become increasingly important is intersectionality, against the backdrop of realising that disability does not exist per se, but that people with impairments also have different contexts of identity that affect their experience of disability, such as gender, socio-economic situation, migration background, age, sexuality and so on.

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And this is also increasingly supported by research.

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So where do we stand after 50 years of rethinking disability?

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It can be said that within the scientific discourses on disability, the new thinking has largely prevailed. In disability policy, we often encounter a gap between words and deeds.

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And this can also be seen in services for the disabled. There often is a progressive wording, but its implementation is extremely hesitant.

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And even in everyday life, despite a decrease in fear of contact, an understanding shaped by the individual model can often still be observed.

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Nevertheless, it must be said that without the changed view of disability that has led to the social model of disability, there would be no equality and anti-discrimination laws for disabled people, no social discussion about participation in all areas of society, and thereby about inclusion. There would be no Disability Studies and their contributions to this discourse.

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And the UN Convention on the Rights of Persons with Disabilities would not exist either.

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Thank you for your attention.