Everyone Has Something to Give. Living with Disability in Juchitán, Oaxaca, Mexico

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The following reflections arose in the course of my research in the context of the German Research Foundation (DFG) project, *The women traders in Juchitán*. My interest in the topic of *disability* developed somewhat coincidentally. The sociological-ethnological research project was concerned with the matriarchal structures of parts of the Juchitán population of 80,000 on the Isthmus of Tehuantepec, maintained by the Zapotec lifestyles of the peasants and women traders. Accordingly, it was the specific normality of these parts of the population that I was looking at, and not the various forms of *deviations* in that society. At the same time, I could not avoid being aware of handicapped people, since they participated with all the others in everyday life completely as a matter of course. 25-year-old Paco, who would be regarded as mentally handicapped in Germany, goes around town on a tricycle with a trailer and sells cheese. Lupita, who is also "mentally handicapped", sells tortillas (maize pancakes) for her mother in the neighbourhood after school. The homeless woman who comes from Chiapas from time to time, stays around the cooks at the market and *has her fits* now and then, i.e. curses everyone loudly, is employed by the cooks to wash dishes and clothes, receiving meals and money in return. A woman who cannot walk sits at a window looking onto the street and embroiders high-quality blouses of the kind worn there on festive days. Carmen and Monica, both also "mentally handicapped", go round the neighbourhood when they come home from school like the other women of Juchitán, who have finished their work at the market by the early afternoon, sit with groups of people relaxing in hammocks and butacas (low chairs with reclining backs), listen to the conversations, observe, say something themselves now and again, keep an eye on the small children and occupy them.

Some Methodological Reflections on the Research into Concepts of Disability in Juchitán, Mexico

After the conclusion of my research on the mother-centred social structure of Juchitán, I began to analyse my observations on the absolutely natural way of dealing with disability there in the light of my knowledge of the social structures. In so doing, an interesting dynamic emerged for me with regard to the question of what I was in fact researching in Juchitán, against which personal and foreign backgrounds. How is it possible for me to investigate disability in a society whose own language (Zapotec) simply does not include this generalised category at all? Although individual defects in physical and mental functions are named (deaf, dumb, limping, to a certain extent *idiot*, see below), *disabled person* does not exist. And why am I interested in how disability is addressed *there*? The motive can hardly come from that part of the population on which my research centres, since they do not know the problem of disability in the way I perceive the phenomenon. Thus it must arise from experiences in a social and cultural environment which *does* distinguish between the disabled and non-disabled in word and deed. What, then, am I investigating in Juchitán? The phenomenon which *our* society terms disability. Why? In order to make it a significant concept (in the sense of George Herbert Mead's significant symbol) in Juchitán too? This is of course not my motive; so my motive can only be to use the absence of the distinction in Juchitán as a basis for reflection on the definitions, differences and delimitations known *here*.

This self-reflexivity on the basis of a cultural comparison is what I would like to call the methodology of my procedure. It is through the analysis and knowledge of another culture that one is able to explore one's own reality with fresh eyes. Involvement in and openness to the other culture, together with the willingness to question one's own, are the necessary preconditions. Both make it somewhat difficult to establish a consensus about such a methodology; the impression arises of wanting to represent the non-Western culture as *good* or *better*, the Western as bad or worse, which would merely be the reverse of one and the same *modernisation theory perspective* – which regards the developed world as the better, and the less developed as the worse. Claude Lévi-Strauss aptly called attention to this dilemma, and formulated this solution:

> Other societies are perhaps no better than our own; even if we are inclined to believe they are, we have no method at our disposal for proving it. However, by getting to know them better, we are enabled

> to detach ourselves from our society. Not that our own society is peculiarly or absolutely bad. But it is the only one from which we have a duty to free ourselves: we are, by definition, free in relation to the others. We thus put ourselves in a position to embark on the second stage, which consists in using all societies – without adopting features from any one of them – to elucidate principles of social life that we can apply in reforming our own customs and not those of foreign societies: through the operation of a prerogative which is the reverse of the one just mentioned, the society we belong to is the only society we are in a position to transform without any risk of destroying it, since the changes, being introduced by us, are coming from within the society itself. (Levi-Strauss 1973: 393)

It is in this heuristic spirit that, with reference to Juchitán, I propose in the following to use sociological instruments to make visible the structures of a society in which a distinction between the disabled and the non-disabled – comparable to that made in our society – is not known. Conversely, the insights obtained make it possible to consider the distinction *we* make (including the definition of disability) in a new light. A methodological procedure of this kind means seeing disability not only as a physical, emotional or mental characteristic of a person, but also as a socially produced state. We need merely to consider the history of the definition of disability in Germany to establish that the concept is not only a very recent one, but also that it varies. Statistical surveys lay down differing criteria to distinguish between disabled and non-disabled, depending on which labour market policy motivated them (see Bintig 1980). Those concerned with the education of the disabled are continuously re-defining disability. One criterion alone runs through all definitions, namely disability as the impaired ability to take part in economic and social life. Meaning patterns belonging to Western industrialised society are both manifestly and latently apparent in the definitions: anyone can take part if they are able to do so independently and without the support of others, if they are fit for work and able to withstand the competition and pressure to achieve (cf. in this regard the critical analyses of Iben 1983; Deppe-Wolfinger 1983; Stroot 1998). In Juchitán however, we find a different concept of independence, work and economy; and thus it is not surprising that the people there do not make the same distinction.

People with Disabilities Have a Place in Juchitán Society

If people are able to work in Juchitán, they are supervised, if necessary, by members of the family and neighbours. At the same time, people in Juchitán need not necessarily work with the sole aim of making money, in order to be valued by family and society. There is a broad spectrum of activities that earn recognition and are not considered less important than work at the market. Activities such as giving each other time and attention, massaging one another, mutual visits, taking part in festivities, helping neighbours prepare for festivities, or simply sitting with others and exchanging views. In Juchitán, every single person is able to give something – or as we would say, to achieve or perform – just as they are, no matter what their peculiarities or special characteristics: like the alcoholic or people who can't work at the market "because their hand is too heavy, when they have to serve a customer" (Otilia). If they are bedridden, they are cared for at home. Things become tight when families cannot afford to free members to do the caring, or if they are not integrated into a social network. Cases of this kind, in which disabled people are neglected, do exist in Juchitán. However, it can be assumed that the number of such cases is far below the national average, since it has been shown that people's existence is far better assured than in other parts of Mexico (Oswald 1997). The flourishing regional economy (cf. Bennholdt-Thomsen 1994) safeguards the independent culture of dealing with disability.

Going by the daily rhythms of the women traders of Juchitán, it is not surprising that people who need support are supervised and cared for in the family. The economy is based very fundamentally on the production of immediate necessities. What women produce in the household and men's agricultural and craft products are sold by the women at the market. With these kinds of home industries, with work in the field, in the home and at the market, it is quite possible for children, the old or a person with a disability to be given tasks suited to their abilities and thus for them to be included in everyday work. In addition, living arrangements are relatively open, so that work in and around the house is visible, and spontaneous help with housework or caring is possible. Nevertheless, if we describe the part that disabled people play in social life in Juchitán purely on this level, it means we are failing to grasp what specifically characterises Juchitán normality and we are still thinking in terms of criteria applied here, in Germany. People participate and are not seen as a problem as long as they contribute or their care can be relatively easily organised; but such a description would not do justice to the

Juchitán yardstick, in terms of which people's participation is not in question at all. In Germany we speak of *integrating* disabled people, and in so doing, make it clear that they do not automatically belong to normality. Even if they are integrated, this does not disguise the fact that that integration presupposes segregation, non-integration, dis-integration. What makes daily life in Juchitán so fascinating for inhabitants of the Western world is precisely the *normality* of the *otherness*, the complete naturalness with which people adjust to the particularity of another person without reducing her or him to this feature or putting her or him in a pigeonhole.

In Juchitán's Subsistence-Based Economy, Everyone Is *Needy* ...

In the research project mentioned above, we had been analysing Juchitán as a subsistence-oriented society. This subsistence orientation manifested itself in the fact that production and trade did not function according to the rules of the free market. The aim of activities on the land, in the workshop or at the market is not to generate surpluses in order to reinvest, and thus increase income. Instead, the aim is to provide for daily needs. If the women traders do have surpluses, these are shared out in the form of feasts. Holding a feast means putting oneself in the debt of the people who come to the feast, help with the preparations and contribute a sum of money. They in turn will also hold feasts in order to claim what is due to them. This principle of reciprocity permeates the whole of people's daily lives with one another, creating mutual obligation and preventing thoughtless over-privileging in competition. It stops people from going it alone, both in the way they live their lives, and in upward mobility. On the contrary, the Juchitecos continuously renew and confirm their mutual dependence. Juchitán differs in this from the other prestige economies found in ethnological analyses, economies in which existing wealth, for example in the form of copper plates, weapons or carvings are wasted and destroyed in order to challenge *equals* (cf. Mauss 1990: 85f.). Instead, the Juchitecos enjoy music and dancing, eating and drinking to excess. Immediate human needs are at the centre of the festivities; for the satisfaction of these needs, networks of dependence based on reciprocity are formed.[1] My thesis is that the Juchitecos' way of accepting disability as a part of everyday life in fact expresses a subsistence orientation, not only because it places the immediate satisfaction of human needs at the centre of social activity, but also because it acknow-

ledges the place of need, and needs, and, not least, of dependence on one another. Not only is food a means of communication at feasts and at the market, but mutual dependence is also ritualised. The need for help and support are not branded irritating irregularities in the smooth performance of daily work; instead, such needs are seen as normal, and can be compensated for.

During my stay in Juchitán I observed several times how friends were nursed and cared for at home after an operation. In every case, female relatives doubled the time of convalescence for which the doctor had ordered the women not to work or exert themselves. The convalescents were relieved of all activities, and helped to shower and dress. On the other hand, they evidently found it no problem to accept the extensive help given. In my nearly two-year stay there, it was a difficult process for me to gradually understand that the people of Juchitán see themselves far less as self-reliant, autonomous and independent, or try to be thus, than as needing help and support. The Juchitecos do not have the idea of *being able to make their way alone* – not even in the literal sense. In fact, people continuously accompany one another (Holzer 1996: 8f.). People who need help and support are thus simply not noticeable; something which is echoed in the kinds of institutions found in this city. Although in addition to an orphanage there has been a *special needs* school complex catering for children and young people with various disabilities there since 1986, there are no old people's homes, nursing homes or homes for the disabled.

... So There Is No Division between *Able-Bodied* and *Disabled* There

Dividing people into ones who live their lives autonomously and independently and ones who aren't able to or else need support makes little sense in Juchitán. The Zapotec language contains no expression which could classify disabled people as *the disabled*; instead it has only a few specific terms for various forms of disability. There are expressions for people who lack hearing, who can't speak, who can't see and who limp. Physical functions which are defective are described, but at the same time differentiated from functions which are not defective. Thus the blind cannot see, but they can speak, walk, and so on. Apart from this, the language has an expression for those regarded as *idiots* (gichaa). *Gichaa* has discriminatory connotations. The word does not refer so much to a permanent state as to a mood and is directed against another person in a

specific situation. "People who are not handicapped are called *Gichaa* when they anger others or their behaviour is impossible," a cook at the market explained to me. Asunción Regalado, the mother of two pupils attending the special school, gives a reason why she finds the term particularly annoying. She tells several stories in which angry acquaintances or neighbours call her daughters *gichaa* in order to hurt her and her family. She feels very upset about this type of animosity and malice, since she is highly regarded by all. At the same time, another element of the same reality is nevertheless that the young women are not (and cannot) be specifically referred to, they cannot be told apart in other ways. They are Carmen and Monica, the daughters, granddaughters, nieces of ... . Other people cannot refer to their *disability* in the Zapotec language.

On a Zapotec leaflet inviting people to Open Day at the special school, those in charge refer to the pupils as *gichaa*. "I drew the social worker's attention to the fact that she ought not to use this word. However, to this day I haven't managed to subdivide the word more finely in Zapotec, and to find different words for slighter and more severe disabilities," said Ms. Regalado with regret. Here she was also addressing a central dilemma which has strongly influenced both her and her daughters' biography, particularly in connection with the creation of the special school. When Ms. Regalado's daughters were five and six years old respectively, they spoke very badly. For this reason, Ms. Regalado wanted to have them examined in the state capital; she was opposed by her husband and all the rest of the family. "The children are healthy, they are just late speakers, they are not ill, that's the way they are, why do you want to drag them all the way to Oaxaca?!" were the "arguments" against seeking a diagnosis. For the (extended) family, the girls are *normal*, and thus do not need any specialised help or education. However, once disability actually becomes a concern, it starts to seem important to differentiate between types and grades of disability. This became a concern when the question of having the children educated and (differently) helped and trained in the special school established for this specific purpose arose.

In Western industrialised society, the differentiation between types and grades of disability goes hand in hand with laws which promise equal rights and state support for all. Ever minuter definitions, criteria and units of measurement for grades of disabilities consolidate their status as such. The range of people who are supposed to be disabled expands and the paradox identified by Stiker is established, "that they (i.e. disabled people, B.H.) are designated so as to disappear, they are named so as to go unmentioned" (Stiker 1982 in Ingstad/Whyte 1995: 8). With the category

disabled, *Others* are created. All attention is drawn to the imperfection, and all abilities and individuality disappear behind it; and greater differentiation does nothing whatsoever to alter this.

In Juchitán, People Are Not Reduced to Their Disability ...

Most methods we use to supposedly bring disablement closer to *being normal* – e.g. earning your own money, schooling and special assistance programmes – have nothing whatsoever to do with the normality of disablement in Juchitán. Erving Goffman's concept of *stigmatisation* helps somewhat in trying to describe how being normal is expressed there. He describes stigmatisation as the process whereby our society transforms otherness into an outsider status. Here he is referring to the process in the social interaction in which the disabled *alter* is reduced to her or his disability and the range of mutual interactions which would otherwise be possible is ignored. The person reminded of her stigma in this way knows that she is conspicuous, and also knows that her *alter* knows that she knows. This is not a word game, but instead describes a situation which is tense and not *normal*. The *perfect* person can avoid this situation, which is a source of continual uncertainty and insecurity. For the disabled person there are hardly any other situations; she is reminded of her disability again and again (Goffman 1994).

What was observed in Juchitán was different, as a little episode from everyday life will illustrate. Carmen (22) and Monica (21) both want to look for dresses for their birthdays at the market. Both go from stand to stand with me; the young women make selections, try on dresses and bargain. "What does this dress cost?" The trader names the price. "Why does it cost so much today, last week it was cheaper, wasn't it?" This the trader denies. The price, she claims, has always been the same. "Why do you ask such a high price?" The trader names the price which she regards as the bottom line. Carmen leads the shopping trip as a Juchitec trader, not as a pupil of the special school. Everyday normality in Juchitán impresses the observer from a society where she very seldom experiences an interchange like this. The saleswomen do not react to the difficulties the pair have in expressing themselves. Those interactions which are possible simply take place. The shoppers neither have to react to (possible) insecurity on the part of the saleswomen, nor do they seem to think it possible that they themselves could cause insecurity.

... Rather, They Have Something to Give Themselves

To be reduced to their disability would mean exclusion from mutual give-and-take, and that has grave consequences for the happiness and dignity of people.This was pointed out to me by Alicja Schmidt, a friend with Down's Syndrome. She and her husband accompanied me to Juchitán in 1995. Both are members of the association *Disabled helping the disabled* (Behinderte helfen Behinderten e.V.) in Bielefeld. In an interview which I conducted with Ms. Schmidt after this journey, she contrasted her experiences in Juchitán again and again with what she experienced at her workplace in Bielefeld at the workshop for the disabled.

> I never ... felt I was being treated as a disabled person. Here [at her workshop, B.H.] you are really treated as a disabled person. You notice it when you talk to people. ..., it's clear from the conversation if it's sincere or not. As if people just say things without meaning them, and I never felt that with the people in Mexico. It's as if the people here don't really take you seriously.

When asked, "So you didn't have the feeling that the people in Juchitán treated you and Wolfgang [her husband, B.H.] as disabled people?" she replied:

> No, I didn't have that feeling. From anyone. It made me so sad, how Chion [Ms. Regalado, B.H.] suddenly came and cried. That saddened me very much. I thought to myself, I'm sure she has a very hard time ... .

Here Ms. Schmidt is referring to a situation when Ms. Regalado, feeling disillusioned and desperate about her husband's behaviour, came into our hostess's yard and let her (i.e. Ms. Schmidt, and not the other women present, although she knew them better) embrace and comfort her. She mentioned this situation with reference to the question whether she felt she was treated as a disabled person, which she denied. It appears that Ms. Regalado removed Ms. Schmidt's status as disabled by treating her as a person who had something to give her, who could help to comfort her. This is evidently not at all a normal daily experience for Ms. Schmidt. Indeed, she criticised the situation in her workshop in the light of what she experienced in Juchitán:

> I don't like to say disabled, because it hurts inside. But the supervisers have already really determined you, laid down that you have to think and feel a certain way. Lately, since we've been back here, ... where I

> work I've noticed that no-one is really interested in the others, and when you have a question to one of the supervisers or something, then they say, Shut up, get on with your work. ... What are you after, do you think you're something special just because you've got married, you're called Schmidt now, and you've dared to go out of the home? But you won't get work anywhere else, you're still dependent on us.

In Germany, Everyday Life in Institutions is Characterised by the Insurmountable Division between Those Who Give Help and Those Who Need Help.

I admit I also have great trouble imagining Ms. Schmidt comforting one of the supervisers in the workshop. Indeed, the distinguishing feature of institutions for disabled people seems to be the unbridgeable gap between those who need help and those who provide it. Since they are defined as dependent, people living in institutions are reduced to taking. Their opposite numbers are independent, self-reliant people who are in the position to help those in need of it. In this encounter, the role of those who work with and care for the disabled, like social pedagogues and social workers, is to give the impression of *not* needing any help themselves. Therefore those who *need* help can't *give* anything to their helpers. This pattern of excluding people from reciprocity because they have been made into *takers* who can't *give* anything, is incidentally to be found time and again in the way people from the so-called *first world* behave towards those from the so-called *third world* (cf. Pixa-Kettner 1988). Widespread attitudes, prescribed state development aid as well as the more seriously-meant aid from NGOs, all formulate the wish to help, and in so doing, only too often merely reproduce the reverse side of the exploitation coin, i.e taking without giving, by giving and not taking. In neither of the cases are the two sides equal. The pattern is so striking, that it would be useful in the further analysis and cultural comparison to concentrate not on those who (appear to) need help, but on the need to *create* those who require help, a need which is so very clearly apparent in the institutions in this society.

A Comparison between Juchitán's Mother-Centred, Subsistence-Orientated Society and Germany's Patriarchal Money- and Commodity-Based Economy

Suppose we compare German society with Juchitán society as *symbolic orders*, as Luisa Muraro has termed them. With the concept of symbolic order, Luisa Muraro is referring to meaning structures which come into being through people recognising and naming – selecting – the diversity of the reality within their social context according to specific patterns of meaning relations (Muraro 1993). Women's Studies in the industrialised countries has, from the beginning, described the *symbolic order* of these countries as *patriarchal*. For example: in them, *work* is accorded great significance but what is perceived as *work* are primarily activities which are either remunerated and/or formally organised, or else those connected with the money and commodity economy. In consequence, many activities are neither seen as work nor properly acknowledged, despite fulfilling basic human needs; for instance the unpaid housework of women (or the area of relationship-creating and -maintaining work). This *mother's work* is subsistence production, in that its immediate aim is the preservation and creation of life, and not the acquisition of money and the production of commodities. Within the patriarchal symbolic order however, it is not *mother's work* that is endowed with life-preserving significance in everyday and scientific/academic thought, but that very work in the money- and commodity-based economy which is removing us ever more perceptibly from what is essential to life (Holzer 1997).

What this pattern of significance expresses, according to Luisa Muraro, is that the "origin in the mother" is not accorded any meaning in the patriarchal symbolic order. In the patriarchal system, the (significance of the) origin in the mother is deliberately ignored. On this basis the potency and achievements of women (i.e. their nurturing, providing and caring activities, and the people resulting from these) are on the one hand neither seen, named nor adequately represented. On the other, people cannot perceive themselves as dependent beings, beings with needs who rely on others, if the *mother's work* kind of subsistence production is not regarded as significant. The figure of the mother complements that of the needful, dependent and helpless creature (child, baby). These interrelations will start to become clear when we consider that section of Juchitán's population which is made up of farmers and female traders. With reference to this section, one can speak of a symbolic order of the mother, since the social, economic and cultural organisation of Juchitán is

structured around a female genealogy. This concept, which refers to the female line of succession (e.g. the mother's name and not the father's is passed on to the children), applied to the social organisation of Juchitán as a whole, means that the mother is present in the symbols of the culture as the origin of individual and community life. That in turn means that the *providing*, *caring* tasks of the mother and the needs she serves have a name and are named; and the pattern of significance is, as it were, woven according to these instructions. For example, the production and distribution of food, which are central to women's work in Juchitán, are termed *work* and *economy* (in contrast to here, where many housewives claim "I don't work", and *economy* is connected with industrial production); and women and the distribution of food they have produced themselves are the centre of festive activities. Or another example: needing help is regarded as completely natural and not treated as an irregularity.

Western Societies Have *The Disabled*, Because *Having Needs* Has No Cultural Status

From this comparison of symbolic orders, it is not difficult to see why the autonomous individual, who is not primarily in need but is instead self-reliant, independent, manages on her or his own, represents the ideal of the patriarchal society. The origin in the mother finds no symbolic representation in the forms of social life (e.g. in language or written and unwritten laws). It is difficult to accept the origin in the mother, and thus oneself as a creature that needs help. But why is it that the autonomous, independent individual finds it so important to reduce people who need support so one-sidedly to their dependence and need of help? Perhaps because people's self-reliance is in fact artificial or only an illusion after all? In order to suppress her or his own dependence, however, the autonomous individual requires a lot of discipline; people must constantly deny their needs and state of dependence. Disability and the way it is dealt with in our society thus possibly plays a role in maintaining the illusion of independence. "The disabled" form the background against which "the normal and healthy" can feel strong and self-reliant (cf. Pixa-Kettner 1981). However, those who *make it on their own* can only stand out in contrast to people who have to rely on others if cultural representation and social acceptance remain withdrawn from the latter due to their dependence and reliance. The stigma of being *disabled* removes the status of being *normal* from needful and reliant people. In a

panel discussion, Alicja Schmidt put it in a nutshell. "People say, *You are sick* – because I'm handicapped – *and so you aren't normal*. Well, isn't it normal to be sick?"

The severely spastic founder of *Danceability* (a modification of the dance-form *contact improvisation*) also brings home to us the fact that *the disabled* exist because people believe that they are not allowed to need others. When asked in a television interview how he, as a *handicapped* person, could perform such feats [i.e. the dance, B.H.], he responded with another question: "What makes you think I'm handicapped? I can say what I need, can you?"

Notes

1 Cf. the analyses of Juchitán's social structure, including: Bennholdt-Thomsen, V. 1994; Holzer, B. 1996. Campbell, Howard et al. 1994.

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