

Struggling **for** **Respect and Dignity**

Strategies for shaping meaningful lives among persons with disabilities and their families in a community on the Mexican south-pacific coast



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Department of Social Anthropology
University of Oslo
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For Robertus.

Abstract

***Struggling for Respect and Dignity:* Strategies for shaping meaningful lives among persons with disabilities and their families in a community on the Mexican south-pacific coast.**

In this thesis I present and treat struggles for recognition and meaning among persons with disabilities and their families in a community on the Mexican south-pacific coast. For people with disabilities, their disability often becomes an imperative status, and they are classified as 'disabled', a label itself of recent historic origin. In this paper I have shown how much agency and creativity, strength and courage it takes for a disabled person to gain recognition with a variety of statuses, as a man, woman, husband, daughter, mother or father.

I have focused on employed life strategies which give people social recognition. For many of the persons presented gender categories, which by others might be conceived of as constraining, seem to be cherished and esteemed. Such categories seem to be experienced as somewhat liberating or even empowering, in contrast to the label disabled.

Embracing typically gendered ways of action seem to be secure paths for achieving social recognition, though the contents and interpretations of these ways vary a great deal historically and situationally.

I discuss the etic/ideological pair *machismo* and *marianismo*, which I argue are relevant for the configurations of gender which we find in my fieldwork area. As Melhuus (1992), I find a mentality and practices dependent on the ideals outlined by Stevens (1973) as marianismo, to be pervasive among many of my female friends and informants, although they do not belong to the same socio-economic class as Steven's sources did. In this environment of rural poverty women are active agents, although many employ culturally pre-shaped modes of action and behaviour, primarily connected to the role of mother, the status which most entirely seems to determine women's futures and options.

In analysis I have been looking at practices of *risk-taking* and *suffering*, which I see as epitomes of machismo and marianismo respectively. Suffering, though an aspect of both men and women's lives, seemed to be employed as a verbal strategy primarily by women.

One can see more disabled men than women in Mexico, as in many other parts of the world. This is partially a problem of representation, but what I primarily want to point at, is the fact that more men than women end up injured or disabled as victims of accidents and social violence. I see this phenomenon as a manifestation of cultural models of male action, which seem to highlight variations of risk-taking as a manhood test.

As Melhuus and others have pointed out; men are here traditionally valued in terms of masculinity, as much or less of a man, while women are evaluated morally, as either good or bad. These cultural stereotypical evaluations of women and men seem to be highly relevant for people in my field settings, though alternatives to hyper-masculinity and –femininity/motherhood do exist and develop.

The rehabilitation centre Palapa Papaya, where I undertook fieldwork is one place where alternative gender relations are welcomed and played out. The centre also represents a level playing field where processes of recognition are enabled.

As an institution Palapa Papaya is a diverse field, in which actual content and policies are changing. One aspect that remains is nonetheless the centre's role as catalyst for change, in individuals' lives, and increasingly in practices and attitudes of collective or cultural character.

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It is almost unbelievable that this project is now closing up. I look forward to becoming a good mother, again.

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Struggling for respect and dignity:

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Introduction

My objective in this thesis is to present struggles for recognition and meaning among persons with disabilities and their families in a community on the Mexican south-pacific coast. I will analyse these struggles with the help of anthropological methods and concepts at an individual and structural level.

Living with a physical or mental impairment often represents a social handicap, or drawback, for the persons directly and indirectly affected, irrelevant of where they live in the world. What is *conceived* as disability are nevertheless not the same phenomena in every culture, and the social restraints people with bodily or mental differences live under, are even more varied.

In this paper I will treat people with bodily differences, sometimes accompanied by mental differences. I focus on are these people's social relationships, their struggles for social recognition, and sometimes even more their family members' life strategies

In the article "Suffering and Its Professional Transformations" Arthur Kleinman (1995) warns that ethnography participate in a professional transformation of an experience-rich and -near human subject into a dehumanized object, a caricature of experience, "when illness is reinterpreted as social role, social strategy, or social symbol... as anything but human experience." (Kleinman, 1995:96). The author compares an "anthropologising" of distress in persons to a biochemical medicalisation of suffering. He therefore suggests drawing upon experience-near categories in theorising, "to resist the tendency toward dehumanizing professional deconstruction," (ibid, 97) and simply to become more self-consciously reflective about the human core of human experience. One must identify *what is at stake* for one's research-subjects, and use this as basis for analysis.

I do not intend to dehumanize my subjects of study, and I will therefore let their own voices be heard extensively. In an attempt to transform real life into science, to move from practice to theory (Bourdieu 1977), some sort of deconstruction is necessary in order to draw out interpretations and meanings.

What I see as being vitally *at stake* in the lives of the persons who make up the empirical foundations for my thesis, is their struggle for respect and dignity among their fellows.

A search and need for social recognition is nothing special about these people only; it is a panhuman feature, and also something humans share with many animals. "On the intimate level; we can see how much an original identity needs and is vulnerable to the recognition given or withheld by significant others." (Taylor, 1994:36) However, the ways to obtain, and give, social recognition as a person are to a high degree culturally configured, and those ways are what I will focus on in the following. The strategies

people employ to survive and thrive seem to be adopted from a pool of alternatives, for then to be given personal interpretations. Each person's strategy is not necessarily carefully selected, but is often seen as the most natural way. People are likely to keep to the same path as they have already begun walking, and each person's biography and social capital (Bourdieu, 1977) will influence the development of his or her strategy. Cultural role models of identification, in the form of persons, alive or historic/mythic, close or distant, act as role models for behaviour, and their stories help fuel one's own life struggle with meaning.

Cultural models are not static, though the practice of reproducing cultural forms is a strong tendency in all social fields, enforced by hegemonic structures. New role models are nevertheless likely to be adapted and personal life-stories, and individual practices, help form new alternatives.

The rehabilitation centre *Palapa Papaya*, where I undertook fieldwork, is one agent of change in this respect, together with others, as media, schools, local and state authorities.

I will nevertheless focus primarily on individuals, and the meanings and reasons they give to their life paths.

Circumstantialities

I came to know about the rehabilitation centre Palapa Papaya, where I later was to carry out the broad part of my fieldwork, quite accidentally during Christmas vacations in 1992-1993, when I spent some days in the coastal community of *Aguatepec*, together with friends. A family we learnt to know told us about Palapa Papaya, which despite probably being the biggest institution, work place and activity centre in *Aguatepec* went quite unnoticed by tourists. We learned about the possibility of working and living there as a volunteer, and I believe we were all tempted, not least by the climate and the beauty of the place. Though, I had yet not much of an idea neither of disability nor rehabilitation, which were obvious key words for this establishment.

Accidentally, during the next couple of years after this first visit to *Aguatepec*, I was to experience a state of being that had a lot to do with both disability and rehabilitation. When I returned to Norway after finishing a student exchange period in Mexico, I was involved in a serious car accident, something that caused several physical and also psychological problems, and I needed months of hospitalisation and two years of rehabilitation therapies following that. Afterwards I said I was glad it had happened in Norway, because I received good medical and other professional help, for free, but I also got curious

about what would have happened in a similar situation in another part of the world, for example in Mexico?

Two years after my accident I was pretty much rehabilitated, even though it was still hard to accept that I could not be just as physically fit and able-bodied as before. I felt a traumatic loss, which I experienced to share with other rehabilitation patients in Norway. During fieldwork for this thesis several of my informants in Aguatepec would tell me about similar responses after experiencing serious accidents or illnesses that resulted in disabilities.

With time, however, I came to realise that the rehabilitation process had been a significant learning and sensitivity experience for me. Was this the same for other people who experienced a sudden change in their own health situation, and how do people deal with damages or disabilities that they are born with or grow up with?

How does a disability affect ones family, and how do families influence the lives of persons with disabilities respectively?

In what way(s) is ones identity influenced or shaped by disability? And what cultural role models of identification exist for persons with disability and their carers?

These were questions that led me to choosing the theme for my thesis, and my research question is:

How do disabled people in Aguatepec shape their identity?

Identity is here looked upon as both personal and social, to various degrees influenced by society and culture. Though I am not able to look deep into the psychological processes that go on in identity-construction, my reminder will nevertheless be Bradd Shore's brilliant volume and title "Culture in Mind" (1996), who argues that people's behaviour, thoughts and values are chosen, not always reflexively, from *cultural models* which we incorporate.

In his book on participant observation, Danny L. Jorgensen (1989) argues that one's biography may be used to overcome social distance in the field, and that self-revelation is an effective commonsense strategy for generating rapport. This was a strategy that I employed to some degree during fieldwork. I would sometimes share personal histories, for example from my experience as a rehabilitation patient, on occasions where that felt natural. In these conversations I would also hope that the other person(s) would reveal something personal. Jorgensen says that like all gifts, it [a self-revelation] creates an obligation for the receiver to exchange something – such as a self-revelation of their own – of equal or greater value with you.

I used one opportunity to generate others, and my study was very much shaped in the process. This *snowball procedure* (ibid: 50) is especially useful in anthropological studies, I think, although it can be helpful also in other sciences.

In the use of this methodology one has to be flexible, and continually adjust plans to the situations that come up. It is important never to lose focus completely, although focus quite likely might need adjustments. My participant observations were quite open or “unfocused” in the beginning. In fact, almost without noting, my focus of interest also shifted, from attitudes and behaviour towards disabled people, to identity creation and alternative life strategies among people with disabilities. In my analysis attitudes and behaviour will still be present, but the main focus will be on identity creation, meaning, and alternative life strategies.

Chapter I: Themes

Attitudes and practices related to children with disability

In Mexico, as in many other countries of the world, there has been a practice of hiding away people with disabilities. This has happened on the household level; family members – often parents or grandparents – have hidden away children and grown-ups with disabilities; and to a certain degree this still happens. I saw some instances in the two communities where I worked, and the youngsters I learnt to know at the rehabilitation centre Palapa Papaya told me that this practice is still common in the small, isolated communities where the majority of the users of the centre come from. Living inside an institution can also often be qualified as “hiding away”, as one mother who was living inside Palapa Papaya with two teenage children explained: “...there are many mums in the villages who go hiding their child... they don’t let them out in public, so people can see them.” “Like my son Mateo, who I am hiding here, but it is necessary.” “He is over there, looking at TV, because that’s his interest.”

In earlier times in Northern Europe, children who were born with visible disabilities were sometimes carried out to die. An explanation to this was that the baby had been exchanged by trolls or fairies, or Satan, and it was thus a “changeling”, and it was said that the newborn was a being from the underworld. In folktales parents were advised to treat these children cruelly, so that their real parents from the underworld would be forced to feeling mercy with their child (i.e. the “changeling”), take it back to the underworld, and return the human – normal – child to its parents.

In Mexico some of my friends and informants reported similar beliefs, but also that these beliefs were changing. They must keep an eye on infants at all times, to avoid *la bruja* or *la llorona*¹ from harming them. As a friend and informant said; “earlier – like ten or fifteen years ago – you could not leave a baby alone, because *la bruja* would take it away.” “People were more credulous earlier.” “*Era mas creída antes, la gente*”. The same youngster in another instance told me that his sister had been stolen by *la bruja* when she was a baby, but that the parents later had found her under the bed. Someone must have removed her, he recounts; because she was not able to crawl by herself yet.

In other parts of the world it is also usual to give explanations for why one should not care for a disabled child.

¹ *La llorona* is a mythical female figure, a ghost who can be encountered at night, wailing over and looking for her children. There exist a variety of versions of this story throughout Mexico, and in most *la llorona* has killed her children herself, but she is regretting, and therefore she can’t have peace, neither after death. It appears that she is most dangerous to men, whom she can seduce, because she is a very attractive woman, and to children, whom she can kill or steal.

Nancy Scheper-Hughes (1992) writes from North-western Brazil, where child mortality was then the highest in Latin-America. The poor mothers in the neighbourhood "Alto do Cruzeiro" from her fictive city "Bom Jesus" gave the high child mortality explanations on different levels, both structural, economical and personal. To an impersonal question about why so many babies die, they generally answered that this happened due to infections and intestine bacteria, something that again resulted from the pigsty they were living in. When the same women later told about their own children's death, this was done in very different terms, on another level. Then it was destiny, or in fact the child had been weak and unviable from the start. Certain illnesses were regarded as very stigmatising, and it was understood that the mothers were afraid that their children would result "worthless", understood as weak and dependent on help for all future, if they were to survive certain so-called child sicknesses. Many such children thus suffered some sort of selective neglect, which for many had lethal consequences.

During my fieldwork I also heard stories where the parents' lack of action in response to a child's health condition could be termed selective neglect. These stories had different motivations and outcomes, of which one was the death of a child. Another consequence was that the child fought harder, proving that he or she could make enormous progress independent of parents.

Nevertheless; what I saw and heard most about during my fieldwork, was parents supporting and fighting for their children, and at the rehabilitation centre Palapa Papaya; especially those children who had a disability.

However, there were instances where parents did not agree to let their child have a medical intervention, because of fear that such an action would harm or kill their child. This attitude was often approved and even insisted on by the child.

A similar instance – but where the child could not state her opinion – was the case of a baby girl who used to attend the early intervention programme at Palapa Papaya once a week together with her mother, sister and grandmother. Her head was oversized due to "water" in her brain, and she could not develop normally as an effect of this. She definitively needed a *valvula*, that is a valve or shunt to drain excess cerebrospinal fluid, commonly just referred to as water, from the brain and carry it to other parts of the body, where it would not be harmful. Her mother wanted to help her, which is why she kept taking her to Palapa Papaya for the early stimulation classes, but the family could not afford a *valvula*. Then the centre's therapist leading the classes where the baby attended wanted to use her *palanca*, which are her network connections, to help the family out. The case was taken up and discussed in two main assemblies at Palapa Papaya, and a solution seemed to be found. The therapist found a doctor who could perform the intervention, and then my own godfather in Mexico City said he was willing to pay for the *valvula*.

The mother was first glad that the family could have the support they needed, but after a while she grew reluctant to the idea, because she feared that the indispensable operation would kill her baby. The baby and her caretakers stopped coming for Early Stimulation classes, and in reality I wanted to go to the city of Comintla to search for the family, and try to persuade them to opt for the operation. Though, I did not, which would certainly have been way too much intervention, and all one could do was hope that the family would fare well in the time to come, although one knew that they were going through a lot of suffering.

Role models, identification - recognition

Schematically speaking one can say that there are positive as well as negative personal role models in the world. A role model is a person who serves as a model in a particular behavioural or social role for another person to emulate. Sometimes one looks for role models to guide one's entire personality, be that in one or several persons. A role model is often a person close to oneself; a family member, a friend, or it might also be a public person, like a sports hero or a famous artist.

Primarily I want to look at what I see as "positive" role models, persons whose actions or lives seem admirable and thus one might try to repeat them, or do something similar as them. In the following I will also use a distinction between "close" and "distant" role models and say something about the importance of having role models or "heroes" who have a disability, both for people with and without disabilities.

To what degree do role models with disability exist, and what do they eventually mean to other people with disability?

Given my concern about disability, I had a preliminary idea that the Mexican artist Frida Kahlo, who had a double disability, resulting both from illness and accident, would serve as a probable "distant" role model of identification for my future informants. I imagined she had to be a powerful cultural model of emulation for people with disabilities, especially for women, but I soon found out she wasn't. No one mentioned her, and when I asked my informants about Kahlo and her eventual impact, most did not know her, and none related to her as a cultural model or symbol for identification.

During fieldwork I nevertheless participated in a colloquium concerning Disability, Education and Culture at the National School of Anthropology and History (ENAH) in Mexico City. There one session was dedicated to a comparison of the lives and works of Frida Kahlo and the Argentinean painter Anita Malfatti, who also had a disability. Their power as symbols and role models for people with disability was not discussed explicitly, but it seemed clear that they *do* function as such for persons who possess the cultural capital of education and belong to the upper strata of society.

Risk

Risk-taking seemed to be a *practice at stake* for many of my male friends and informants in the field, as it seemed to enhance their social recognition as men. I find the practice of risk-taking connected with an ideology of machismo, understood as hyper-masculinity, in the field where I worked. Risk-taking is thence primarily and almost uniquely attached to men's life-worlds. This was manifested in different fields and in different ways, as through violence, sports, life-saving and drug use.

Marit Melhuus (1996) has claimed that men are classified along a continuum, in positions relative to each other, as either more or less a man, whereas women appear to be classified discretely, as either decent or not decent. Therefore masculinity can be – and is – continually (con)tested. This is a proposition I find to suit my field setting as well, and I argue that men's risk-taking is a test of masculinity that provides them social recognition and respect.

David Gilmore (1990) defines machismo as a masculine display complex involving culturally sanctioned demonstrations of hypermasculinity, in the sense of both erotic and physical aggressiveness. Gilmore shows in his culture-comparative survey that being accepted as a "real man" involves tests of action and proofs of worth in most societies, but he also provides illustrations of societies where the notion of masculinity as a test is virtually absent. This indicates that femininity and masculinity are not biological essences but cultural creations.

Sports as means to strengthen identity, or Sport Idols as Role Models

One situation where people with disability in my fieldwork setting meet is for doing sports. Several young wheelchair-users met, more or less regularly, to play basketball. The ones forming the base were five of my male friends and informants, and two girls used to join in when they were home from the city where they studied. Two of these men are paralyzed from the waist and down due to spine injury as a result of severe accidents and they are dependent of their wheelchairs to move around. The other 5 have got polio sequels, and only the two girls used their wheelchairs in most daily situations, while the three men occupied wheelchairs to run long distances, and for practising sports. If they needed an additional person in order to set up teams, a non-disabled person could also fit in, but preferably using a wheelchair. Temporarily patients or visitors at Palapa Papaya were also welcome to join in.

Nonetheless, not every person with disability would meet on these sporting grounds. One's vigour, wellbeing and health were decisive, as well as spare time. Wellbeing will often come as a result of engaging in sports, but this quality is also a foundation for performing well in sports. Good performance in sports seemed to be experienced as utterly satisfying by the persons playing or competing, and to a somewhat similar degree people can experience sports performance as unsatisfying, or even humiliating.

That might be the reason why other persons, who were not especially strong or talented, chose not to engage in sports. This seemed to be the case for some (2 or 3) of the neighbours of the centre, who were occupied in the sector of service and commerce in the village. Another critical theme was pain and pressure sores, which are setbacks that some of these persons have, and then physical activity might be harmful.

Life-guarding

Life-saving was a phenomenon much discussed and at stake in the village, and also a manifestation of risk-taking or manhood test, which enhanced practitioners' social recognition and respect. The village beach is dangerous due to strong undercurrents and open ocean touching the sand. Palapa Papaya was closely involved with the life guard group from the start, and they still use to train both the voluntary life guards and their own volunteer workers in the CPR (Cardio Pulmonary Resuscitation) technique.

During my fieldwork one person with disability was actively part of this group, and others were loosely connected. Their engagement seemed significant for their self-worth, and it was also a source of pride for their families, friends, and people at the rehabilitation centre.

Substance use

I choose to understand the use of toxic substances as a strategy to prove manhood, and as a means to escape everyday pressure to organise one's future, and I see drugs primarily as a risk-seeking strategy. For men it is also a matter of meeting existing social expectations, explicit demands from friends or accomplices, and identification with cultural role models. This practice is also primarily a men's thing, but in the only case where one of my female friends and informants admitted past alcohol-abuse, this strategy was explained as an escape from personal suffering.

Suffering

Suffering is a human universal, but the modes and causes motivating, legitimising or putting restrictions on expressions of suffering, are relative to culture, context and gender. There are a variety of modes of suffering, as well as causes, and both women and men do suffer.

As culturally enforced strategy, suffering is different from the practices of risk-taking, which above all is related to men's life-worlds, and the practice of suffering seems primarily linked to women. There is

however a link between men engaging in risk-taking as a means to escape personal and social suffering. Though, this is usually not accounted for as suffering.

In the following I will be approaching the phenomenon of suffering (*sufrimiento*) as an emic illustration of *marianismo*, which I accept as parallel to *machismo* in my field setting (Stevens 1973). Suffering and self-sacrifice were central phenomena and themes in the lives of most of my female friends and informants.

Ian Craib, treating modern personal identity from a sociological and philosophical stand said: "The discovery of freedom is the discovery of multiple forms of suffering and perhaps the most meaningful personal sense in which we can talk about having an identity is that our identity is the result of the quality of our suffering." (Craib 1998:177) This quote is capturing an essence of the persons and lives I came close to during fieldwork, and who will dominate this paper.

Chapter II: Methodology and self positioning

Cultural norms are relative, and as I understand it this is also the case within a culture or society, in that norms can have special situational and personal interpretations, as well as fields of influence. All fieldworkers will certainly not interpret the same actions and settings in the same ways either, just as they will do some subjective choices for their own line of actions, that is, methodology.

During fieldwork I felt quite comfortable, and I did not experience so much of the struggling that I had been taught to be prepared for. On the other hand, being aware of possible problems probably made me more sensible to the field, which I believe was a strength that helped me reflect more consciously on my own conduct during fieldwork. Fortunately I did not feel like “matter out of place” in the local setting, and I did not have to strive hard to create a more or less “natural” place or category for myself as a researcher to fit into. Using an *overt research strategy* (Jorgensen 1989:46) here did not pose a problem. What I felt as most problematic during my fieldwork was not to gain access to the field, but rather to create and maintain a distance to my informants in the field. Many of them soon became friends, and I will not try to hide that. Though, just as Amanda Coffey (1999) states; more often than not the reason for the initiation of a relationship was tied up with the actual pursuit of fieldwork.

John M. Johnson (1975) says that “the quality of data is improved when the participant observer establishes and sustains trusting and cooperative relationships with people in the field”, and I cannot but agree. I needed to come close to my informants, and it became part of my research strategy. Actually it felt quite natural and fun to spend time with most of my informants, and the fact that I liked many of them as persons must not be a disadvantage. Though, my notes are probably in part coloured by their points of view, and this is certainly not objectively “fair” to others with whom I did not interact so close. I will take this into consideration as best as I can in my analysis.

I chose the settings because I found them both interesting and stimulating, and I thus had a positive attitude before digging more into the reality of people with disabilities.

In one way I can say that the setting chose the topic, but also vice versa. I chose to realise my fieldwork in two communities because of some prior knowledge and experience in both. I liked these places very much, and I thought I would like to live there for a longer period of time. In the two communities where I carried out fieldwork I could also see other topics begging to be explored, like migration, modernity – tradition, eco-tourism, globalisation, substance abuse, etc. What made me choose to explore disability and identity construction, and not one of the other themes that I found interesting in these settings, was a matter of personal choice and circumstantialities. Perhaps my own experience first

as patient, and later as “rehabilitated”, was the leading factor in my decision-making. I felt close to the topic in a very physical way.

Also the story of a young man, who later would become my friend and assistant, inspired me to choose my topic. On a travel to Mexico in December 2000, a year prior to my actual fieldwork I got to know this young man, let me call him Timo.

Since I already knew Mexico after living there for about a year and a half on earlier occasions, I felt socially bound to and wanted to go visit my old friends before visiting my intended field. Thus I travelled from the south of Mexico City, through Cholula, Puebla, to the city of Oaxaca, before I reached the Oaxacan coast where I would check out the possibilities of doing fieldwork.

In Aguatepec I met Timo, who was staying down at the beach at the time, where he was living with his sister’s family, and giving them a helping hand with the tourists. This was the beginning of the tourist season; in early December. Also Timo’s best friend, Pedro, lived and worked at the same place, and that is also where I, quite accidentally, had decided to stay, and I rented a small palm-hut with Timo’s sister.

What made Timo different from others was not only his disability. He was a longhaired always-smiling youngster, around twenty, who always had the time to talk. He made a good impression on me, but to be true his extremely skinny leg did frighten me a little bit. However, it also made me curious. I asked him about it, and I got a bit of his life story. In short the poliomyelitis virus had infected him when he was a baby, and due to this his right leg had never developed a muscular structure, and he had not been able to walk until the age of ten or twelve, after long time hospitalisation with operations, treatment and rehabilitation. After that he had obtained leg-braces and crutches. He told me an aunt of his had organised a big party, where all the money that was collected helped finance his hospitalisation, and the local rehabilitation centre Palapa Papaya added the rest.

Timo’s story was a tough one, but I also found it full of hope. I was impressed by hearing it and not least by seeing how well this young man seemed to handle his daily life, despite of his disability. His story gave me extra inspiration, and I got more curious about looking into the lives of people with disabilities. It also seemed viable for me to work out a plan in cooperation with the rehabilitation centre Palapa Papaya.

Timo had been associated with Palapa Papaya right from its beginning, but now he stressed that he did not have much to do with the centre any more. He got affectionate when he talked about the founder of the centre, Palmer Brown, who had died a few years after Palapa Papaya was formally established. The founder had been like a father for him, Timo said, but he was not very positive to the changes that had been happening at the centre afterwards.

The rehabilitation centre Palapa Papaya had caught my interest nine years earlier, when I first visited Aguatepec, on a short trip during my year stay as an exchange student in Mexico. Then I had visited the

centre personally 4 years later, on my first return to Mexico, in autumn 1996. Between these two visits to Mexico I had suffered an accident with long time rehabilitation following it. This had made me more open to and interested in the lives of people with disabilities.

After choosing my topic I also thought that it would probably be fruitful to go to different localities, to try to live up to anthropology's comparative aspirations. That is, I wanted to be able to make comparisons between two communities which were geographically close, and as good as parallel in size, and thence say something about whether my first findings could be generalized or not. This is why I ended up in two different localities, though the concrete plans for the second setting came about while I stayed in the first place.

Due to the tourists or voyagers who conquest the beach of Aguatepec periodically, and not least because of the recent history of the village, where foreigners have settled more or less on a par with people from the region, there is something of an "international atmosphere" to the place. This made my presence as a foreigner here less conspicuous than it could have been in another locality.

Aguatepec is a special place. It is one of the very few clothing-optional beaches in Mexico, and this seem to be the main reason that the place exists in the vocabulary and imagination of many people who have never been there. Nudism is not the rule at the beach, but none are surprised of seeing a naked sunbather. Local people don't bathe without clothes, and the volunteers at Palapa Papaya, who all stay at the place for at least a half year, do normally follow the clothing norm, and the nudism is more present in discourse about the place than in effect. Aguatepec is a particularly popular destiny for homosexuals and the consumption of drugs is probably higher than average. There are two yoga schools in Aguatepec, Nirvana yoga school, founded in 1975, was the first establishment in what would later be considered a village. Here no drugs or alcohol is tolerated, nor is nudism.

There are always a few travellers who come in off-season, and some people just keep on staying in Aguatepec after their vacations. Some of these might start working as volunteers at Palapa Papaya, though the majority of volunteers arrive directly to the centre. In addition there are the students at the new Ocean University. All these categories of people are generally young and most of them come from outside of the region, both nationals and foreigners.

Although the rehabilitation centre Palapa Papaya in many ways can be seen as a community in the community, the world outside their imagined window, that is the community of Aguatepec, is part of the larger setting. The village is perceived as "alternative", just as the community of Palapa Papaya is, though in another way.

During my stay in Palapa Papaya, which lasted for 5 months, I worked as a volunteer 4-5 days a week. I also lived at the centre, where I shared a room with Noelia, another international volunteer from California, USA. Being an “International Volunteer” at Palapa Papaya was a category that almost embedded my whole existence while staying in Aguatepec. I found it meaningless to fight against this category, and to be honest I felt it quite comfortable as well. After all I was an “International Volunteer”, only with a second mission as well.

I could have realized my fieldwork without serving as a volunteer at the centre, something that might have been seen as more “objective”, but I found it truly beneficial to work there, and I was also satisfied with in this way paying something back to the centre. Working as a volunteer made my interaction with people easier, thus it served as a strategic tool rather than as an obstacle. I was comfortable enough in the role, and I chose to embrace it (Goffman 1959).

I later returned to the village to undertake following up studies on three different occasions, totalling three months. I then lived outside of the centre, at a tourist establishment at the beach, or with friends in “Los Altos”. On one of these occasions I volunteered at a week-long camp for youngsters with and without disability (Easter 2003) and for a month and a half in Spring-Summer 2004 and for one month in November 2005, I visited and stayed at the centre regularly during the days. The coordinator for volunteers actually asked me to fit into the routine work also on my latest visit, but I had to reject his wish, because of shortage of time. On the last visit I instead had the pleasure of following some of my main informants to religious rituals, conducting interviews, and participating in a sports competition.

The category of International Volunteer was quite open. Very different kinds of people could occupy the position, and it could be filled in a variety of ways. In this broad category I will say I actually moved towards a Complete Membership, towards “going native”, as the “nature” of International Volunteers’ work is normally temporally and flexible. Though, in the community of Aguatepec I was not a Complete-Member-Researcher (according to Adler & Adler 1987). In the role I was playing, the life I lived did not entrap me so much that I lost my sense of reflexivity. I kept some communication with fellow students from Oslo, and I also engaged a little bit in the anthropological scene in Mexico, with visits to the two main anthropological schools, the UNAM and the ENAH, both in Mexico City. At the latter I had much communication with students and researchers, and at some point I participated at a conference in Mexico City, together with the general coordinators of Palapa Papaya and my friend and assistant Timo.

I used an officially open strategy of participant observation. According to Adler & Adler’s thesis I estimate I took on a quite Active Membership Role in the community. By taking an overt role, as most AMRs (Active-Member-Researchers) do, this enabled me to bring more of myself into my research

setting. This role corresponds more or less to Gold's description of the "complete participant role" (Gold, 1958).

The process of introduction and acceptance went as follows:

On my second day at the centre I introduced myself and my "project", in the weekly assembly arranged at Palapa Papaya. Presenting my current study was not a difficult task. People here were truly interested in my topic of study, and they had been expecting me. I had made a written, formal application earlier, to which they had answered me positively. Also they had prior experience with students of other disciplines who had come and stayed to collect information for the purpose of writing a thesis. I was explicitly welcomed, and I felt that people who were connected to the centre had a positive attitude towards me from the start. Adler & Adler (1987) says: "They [Active Member-Researchers] generally assume functional, not solely research or social, roles in their settings."

I felt good about conducting normal work at the centre, as the other volunteers. Though, after a while I asked for, and was, a little bit reluctantly, granted one day off a week, to work exclusively with my thesis. This was convenient, while I never had any time off from fieldwork.

There would normally be around ten people working at the centre as volunteers, of whom the broad part would live inside of the centre's area. The huts for volunteers were nice and easy to keep clean. Of course there would be some bugs, a couple of tarantulas, etc., but that is just part of daily life. The other volunteers saw me writing on my computer every night, but during the days I would usually not take notes, a choice that reality had taken for me. A permanent injury of the brain stem – or disability – that I have as a result of my accident makes handwriting difficult for me, and it was thus not viable to take small notes in the moment of participating observation, something that I believe would have disturbed events anyway. I compensated my practical problem with handwriting, writing on my lap-top at the end of the day, and also by bringing a small tape-recorder in my bag. For the topic of study my apparent practical problem did not become as much a handicap as an experience and a point of reference to share and compare with some of my new friends and informants. It certainly could make it easier when explaining my interest in the topic, as well as it could create more intimacy between friends and informants who had a disability and me.

In sum; I fit easily into the category of "International Volunteer" at Palapa Papaya, and all the people at the centre knew that I was also conducting fieldwork (studying for my thesis), as did all the people that I interviewed, and my main informants. I believe my behaviour did not differ much from that of other volunteers, or disagree with what was expected of me as an international volunteer. I hung out a bit more with disabled people, and I did generally not engage very much with tourists, but I did spend much time

with the other volunteers, who also became my friends, and semi-informants. They soon got used to seeing me write outdoors in the nights.

The other field setting, Laguna, where I stayed for 3 months, was different. It was not such an obvious field for doing studies on the topic of disability as Aguatepec had been due to the rehabilitation centre Palapa Papaya. However I wanted to go to a community outside of Aguatepec, to get some base for comparison or generalization, and Laguna was just as good as anywhere else. The two places are geographically quite close, and the one place exists in the local discourse in the other. The temperature is very much the same, and both places are located on the seashore. However, Laguna has got a quiet bay and adherent lagoons that are great for fishing, and the place is not heavily affected by drought as Aguatepec seems to be. Tourism here is more restricted, practically this is due to a quite difficult accessibility, and politically this is probably a well considered choice, as the lagoons here are also a national park that should be environmentally protected from raw economic exploitation.

My friend and assistant Timo was actually the one bringing up the subject of Laguna, and this made it easy for me to suggest, and legitimise, a change of setting. He had been there only once, and he mentioned that seeing him rescue a fellow lifeguard during exercises there had surprised many of the villagers in Laguna. They had not thought he would have been able to act the way he did, due to his visible disability. This sounded interesting to me, and we decided to go there for a weekend, and seek out the place a bit more. We stayed with some friends of Timo's, a young family, and I used the occasion to talk with a representative of the local authorities, and ask permission to come to stay and undertake study. This was easily and informally granted, and the vice-president with whom I talked stated that he found my interest in the poor disabled people to be very gratifying. It came through that he thought disabled people could not manage by themselves at all, something that especially Timo found provoking. I thought it was interesting enough, and I told Timo that he might make people change their view about people with disabilities if he came here, and that I really hoped he could join me as my assistant on a later point, and fortunately he accepted.

The family with whom we stayed these few days were very nice, and they told us that we could come and stay there as long as we wanted, which was certainly tempting, but I wanted to establish a quiet place where I would not be much affected by other people, and quite accidentally we found a two-room unoccupied bamboo-hut on the other side of the lagoon. We talked with the owner, an old mestizo, and he told us we could come and stay there, for free, whenever we wanted.

In Laguna people generally did not see me take notes, but most of them knew that I was there to study. I continued my routine from Aguatepec of writing my diary every night, and often I would also be able to discuss details with my assistant on late evenings. Sometimes I brought and used my tape-recorder during the day, and Timo also helped me take notes at some point.

In general I tried to use much of the same strategies as in Aguatepec, but here I was not able to fall into a broad category – as “International Volunteer” that could give me instant protection, and explain my presence. Here I had to create and define my position.

Laguna also receives some tourists, mainly of the same “category” as Aguatepec. That is, young, “reckless”, and low budget people. There are no hotels, but several *palapas* where one may rent hammocks or sleep in tents. These are opened, or even (re)constructed, prior to the holidays of Christmas and Easter. Some huts or bungalows for tourists also exist. The few people who might want to stay here off-season have to arrange for something else with the locals, which is not difficult. *Todo se arregla* – anything can be arranged.

What was funny was that there was already another anthropology student staying in the community when I came there. Earlier I had heard about him, but he had not been present on my prior visit. Federico was a young man, around my age, from Mexico City. He was looking into the topic of race and ethnicity in the place. Laguna is primarily a black (*moreno*) community, as many of the places on *la Costa Chica*, which represent a sort of enclave on the Mexican South Pacific Coast in the area between Acapulco in the northwest and Puerto Escondido in the southeast.

These points; the growing tourism, seen as flow of people, and the presence of yet another anthropologist acting within the geographical limits of “my field”, made my presence more explicable for people, even though some locals found it odd that I was interested in people with disabilities. However, I talked about Palapa Papaya and Aguatepec to some people who showed special interest in my study. I mentioned my voluntary work there and the connection to my study. Then I said I wanted to get to know how people with disabilities managed in Laguna. Some might have seen me as a delegate from the rehabilitation centre Palapa Papaya, but I tried to make it clear that I was there independently. Though, towards the end of my fieldwork I did arrange for a meeting between people from the community – especially persons with disabilities, authorities, and others who were interested – and representatives from Palapa Papaya. They

were mutually curious about each other's experiences, and discussed an eventual future CBR-project² in Laguna. Both Timo and I were uncertain if this would be the right thing to do, because we did not want to create expectations that might not be met, but in retrospective I think the session was harmless, and hopefully also fruitful for the participants. I also felt that this might be a small paying back to the community; it was my way of acting as *palanca*³. Local people came and joined in on a common practical exercise with a following discussion on disability. Some persons and families were given personal time to discuss their eventual problems in regard to their own or a family member's disability, and learn some practical physical exercises, or they were given advice on how to stimulate children's development, and how to seek further help. The staff from Palapa Papaya was also willing to assist the community in an eventual CBR-project, if the local authorities put in efforts to realise it, but unfortunately this did not happen, because central persons in the community moved away.

The reason that I later chose to discard a separate chapter about Laguna, was that I found the regional comparison was unbalanced. Instead of focusing on intraregional difference, I found it more important, and sufficient for this paper, to focus on differences between men and women's life strategies related to disability and worth, and the significance of Palapa Papaya as a catalyst for change.

While there seems to be real differences in life strategies and orientations between the groups of persons I have dealt with in different empirical chapters, extremes in the configurations of identity, some individuals have also much similarity with other groups. My grouping of persons in different chapters is therefore also somewhat artificial, made for practical reasons.

Methodologically I was looking at the human interactions between the users of the centre [Palapa Papaya] and their importance as role-models in relation to other people, with or without disabilities, especially inside of the centre. However, I also followed or met people outside of the centre, and I thus got a view of their interaction with the world outside the centre as well. In addition I tried to grasp how the centre, as an entity, influence and is affected by local attitudes and beliefs about disability. And in comparison; what could be observed in Laguna? To what degree do "the disabled" really exist as a category in these places?

2 Community Based Rehabilitation projects have been carried out as part of Palapa Papaya's activity since 1994. The programmes are based on a general manual from the World Health Organisation (1989). An essential element of the philosophy of CBR is the involvement of disabled persons in all aspects of the programme, as decision makers, resource persons and trainers at all the stages of planning, management and evaluation. Persons with disabilities should not be passive clients of CBR programmes, rather, active members of the process. Palapa Papaya created own local models of this international trend, in coordination with the communities' authorities and people with disabilities.

3 Here: Beneficial contact and bridge to enable desired communication.

Jorgensen (1989) writes that common knowledge to a large degree can help us judge if the information we get is trustworthy or not, because most of us actually evaluate people and information in daily life. This is what I continued doing during my fieldwork. I think any participant observer must seek to refine and cultivate interpersonal skills for research purposes, which I tried to do, mostly by just acting 'natural', while always staying aware of my not-so-secret "mission".

To some degree I will also use statistical information about the population in the two communities where I conducted fieldwork. Some of this information was gained from the local administrative authorities, by visiting their offices in the evening. In these small places administrative office is not a full time paid occupation, and therefore the people in the staff were not present in the morning, when most were earning their keep in another job. I presented myself and my intentions, and had no problems getting the kind of information I wanted.

During the analysis part of my thesis, I have also found much national statistical information on the internet, from the Instituto Nacional de Estadística Geografía e Informática, INEGI, which I apply to show and explain general socio-demographic features of the region of South Mexico.

I interviewed between 30 and 40 persons from the two communities, using a tape recorder. My key informants were interviewed several times, and from all of my interview subjects I have additional information gained through participant observation, and/or from other peoples' accounts. The interviews differ from semi-structured to not-structured-at-all. Normally I prepared a topic for the interview. Often, though, the interviewee changed topic, or dwelt on just one theme, and I tried not to force the situations.

Almost all interviews were done towards the end of my stay, when I had gotten to know the persons. Therefore I already knew some of the answers to the questions that I asked, but they did serve as a point of departure for further discussions on themes of interest.

At other times, where I found the current and informal conversation interesting, I might ask to tape it, and this was most often not a problem. Therefore I usually carried a small tape-recorder in my bag, just in case.

In daily interaction I would sometimes make my informants remember that I was a student, by saying for example "*eso es muy interesante para mi tesis*" – "that (what you just said or did) is very interesting for my thesis". Sometimes I would ask if it was ok that I taped it, but mostly I would just try to remember. Later, in an interview, I could ask about the full story. I speak Spanish fairly well, and that was one of the reasons why I chose to do fieldwork in a Spanish-speaking region.

There were times during fieldwork when I did not ask to record a conversation, even though I would have liked to afterwards. In the situation, nonetheless, I found it more important to treat people with

respect, so they did not lose trust in me. This attitude hindered me from asking important questions before establishing more intimacy with my informants. When a more steady relationship – friendship – was established, we could talk more freely. There will, in most settings, always be some unwritten norms of behaviour that all individuals must try to adjust to for keeping a smooth conversation. Kirsten_Danielsen (1992) says that this is the case when one is studying his or her own society, and she relates from her own study of old ladies in Frogner, Oslo, where she felt that her truthfulness would be weakened if she broke their conventions and rules for social interaction.

I was not studying my own society, something that, following Danielsen's line of thought, might give me some more room for behaving out of order. Nonetheless, I felt and I do believe, that me being an outsider did not give me any legitimacy for behaving disrespectfully. I think the Adler's (1987) are right when they state: "Data gathering does not occur *only* through the detached observational role, but through the subjectively immersed role as well."

In her essay "*Beyond the words: the power of resonance*" Wikan employs the term *resonance* to suggest how we, as anthropologists, should use own (personal) experiences to comprehend and make resonance with the lifeworlds of the people we study:

To grasp how people experience their lives, we need to attend ... not [to] their terms for gods, institutions, calendars and rituals so much as [to] the concepts with which they feel and think about, and handle, the tasks and tribulations of their individual existences. (Wikan, 1990a:xvi, Wikan, 1993).

This is also what I tried to do. In my text *personal narratives* dominate, as that is where I felt I gained most information, by listening (and dialoguing) with empathy and interest. The narratives I employ are primarily fragments of life-stories which focus on my informants experiences with disability, and their struggles for self acceptance and social recognition. I also include two stories of accidents which happened while I was in the field, to provide a contextual colouring.⁴

As I came closer to my informants, I could also ask more sensitive questions. To generalize I will say that the closer the relation, the more time and concentration it "costs". For example I would normally try to pay my friend and informant Garp a visit to his work area during the day, to see how he was doing, even if I was actually working in another area of the rehabilitation centre. If he was not there I would pass by his house after work to see what was up with him. In the nights that we were hanging out in a local "antro" or bar, I would pass by Garp's, who lived just next door to "The Dragonfly", to have him come with us, or just

⁴ Other types of narratives could have been analysed, as for example the accounts of dramatic rescues done at sea in Aguatepec, or in the lagoon in Laguna. Such stories were told and retold, often on request and primarily by men, who where often themselves the "heroes" or rescuers. The existence and power of such narratives seemed to me as another, and very noble, indicator of the cultural emphasis on male risk-taking.

in order to have a small chat and a smoke under his banana-tree. Though when you invest a lot of time and energy in another person, it usually “pays back”; you get a steady friendship, and then spending time together does not feel like a burden at all. Thus I did not feel my “investments” as any sort of burden.

I also realise that my perception of Tomas, the coordinator for volunteers at Palapa Papaya, had something to do with my choice of friends and informants; as for example Garp, who I was hanging out with far more than Tomas. It seemed that many of the male clientele at the centre were invisibly divided in two, with Tomas and Israel, a social worker, on one hand, and Garp and Timo on the other.

Tomas and Israel were both young men who worked in the coordination of the centre. They had a good agenda, but their means of handling their own positions of power towards others were by many people experienced as patronising, and as a misuse of power, and so conflicts were latent.

Most fieldworkers, for practical reasons, will have to rely to a large degree on notes that are done in retrospective. Making notes takes time. Valuable time, and writing directly in the field setting while interacting with your informants undoubtedly will influence your ability to participate in a relaxed fashion.

As previously mentioned, I chose to write my notes at night, before going to sleep. At the rehabilitation centre Palapa Papaya this would take place in the volunteers living area, where some of the other volunteers some times also would write their personal diaries or letters, or they would just hang out there and relax, and none reacted to my writing, but to the contrary some of them would some times instead help me remember what had happened during the day.

In Laguna, my other field setting, I wrote inside my hut at night, where Timo would most often be present and help me memorise, and a couple of times he would even help me take notes.

Tape-recording will probably also influence the setting to some degree; people know that they are being recorded, and possibly put restrictions on their utterances. That is one of the reasons that I chose to conduct most of my interviews towards the end of my stay, when I had got to know my interviewees well, and they were used to my presence. Everyone tolerated my tape-recording, and as I linked this to disability – that is my problems with writing – it gave me an extra chance of identifying with my theme of interest.

I share Jorgensen’s (1989) view that [all] human relations based on trust and cooperation are dynamic and constantly (or at least potentially) problematic conditions of social life, which require ongoing attention to be sustained.

After a while people will get more or less familiar with seeing you in the setting, and also with your ways of acting, which might include your way of recording.

My fellow volunteers at Palapa Papaya soon got used to, and accepted, my note writing in the nights. I was more uncertain about my friend Timo, when he was joining me as an assistant in my second setting. Would he feel that I was spying on him, or on other people? Fortunately he did not express such a feeling, and I believe I succeeded in acting non-threatening.

I tried to use the tape-recorder in a non-intrusive way as well. I brought it around in a little colourful bag, and I let people “get to know it”. We could play with it, and sometimes we could listen to what we had been saying. One of my friends and informants, who is a part time electrician, would also help me getting to know the machine. In a family that I used to visit, and whom I interviewed, the children and I played with the bag. Sometimes I would bring music cassettes that we could listen to. With friends-informants we could make humorous interviews that we could listen to afterwards.

The interviews with some of my key informants almost took the form of life story accountings, focusing on the question if and how a disability has influenced or changed ones living and identity perception and expression.

What formed my fieldwork were also circumstantialities. As Arjun Appadurai (1988:16) says; “more than with any of the other human sciences, anthropology is based on circumstantial evidence”. The circumstantialities of fieldwork itself seen as where, when, why and whom one studies, will shape one’s notes, and to some degree also the final result, what Lorraine Nencel has also problematised (personal communication).

All persons and sites which this thesis concern are given fictive names. Perfect anonymity is however difficult to attain, without affecting the meaning of the text. Therefore, and as I do not believe that my findings are of strictly harmful dimensions, I know that persons, places and relationships might become recognisable for someone who knows the setting.

Chapter III: Context

The region and country, geography

The rehabilitation centre *Palapa Papaya* is located in *Aguatepec*, a small relatively newly settled village on the Pacific Coast of *Oaxaca, Mexico*.

Oaxaca is one of Mexico's poorest states, and indeed Southern Mexico is often compared to, or seen as a part of the rest of Central America. Countries like Guatemala, El Salvador and Nicaragua are undoubtedly poorer than Mexico as a whole, but Mexico's three southernmost states on the west, that is Chiapas, Oaxaca and Guerrero, show many of the same characteristics as these countries. Poverty, lack of infrastructure and social marginality is more widespread here than in the rest of the country.

The census of 2000⁵ evaluates the state of Oaxaca as the country's third worst regarding citizens' marginality⁶. In comparison, in 1970, 1980 and 1990 it was the worst. Nevertheless, the state's total indicators were better in 1970 than in the following two decades when indicators of marginality rose. Yet it is possible that the census of 2000 was more comprehensive than those covering the previous decades and therefore registered a higher degree of marginality, while, following what inhabitants in *Aguatepec* and *Laguna* told me; poverty and illiteracy had been hitting harder in the past. However, since 1995, the development of Guerrero and Chiapas has been even poorer than the development of Oaxaca, which is shown in the census. What is most significant, however, is that these three states together keep on representing what has been called "the triangle of extreme poverty" in Mexico.

By 2000 more than 20 % of the population of Oaxaca was illiterate, and more than 45 % had not completed primary school. In comparison, less than 10 % of the population is illiterate and less than 30 % has not completed primary school in the country as a whole. In 2000 Oaxaca was the state where most people lived in houses with dirt floors; more than 40 % of the population as compared to less than 15 % nationally, what seems to be accounted for as a main indicator of marginality in official statistics.

In the municipalities where I conducted fieldwork all these marginality indicators were slightly higher than the average for Oaxaca, which is probably due to the settings' relative periphery compared to the state capital, where governmental services, such as education, has a longer history and reaches a higher percentage of the population⁷. Although houses of adobe with dirt floors often is considered to be a marker of poverty, these building materials are well adopted to the climate on the tropic coast, and roofs

5 XII Censo General de Población y Vivienda 2000, INEGI – Instituto Nacional de Estadística Geográfica e Informática.

6 Marginality indexes mainly measures lack of access to services, illiteracy, percentage of people speaking non-Spanish native languages, and overcrowded housing.

7 Education policy, however, seems to represent a major social problem in the state of Oaxaca as a whole, as manifested by the teachers' strike with following social turmoil in the second half of 2006.

of palm leaves are highly appreciated and valued. Though, the poorest of the poor, who tend to be *indigenas*⁸, who live in the mountains and sierras of Oaxaca also tend to have houses with dirt floors, and in those settings this is less pleasant, and a real marker of poverty.

Both Oaxaca as a region and the rest of the country have experienced economic growth and social development in the last decade. Aguatepec is a good example. Coastal communities traditionally benefit from harvesting the sea, and nowadays the sectors affiliated with tourism are even more important in creating employment and money for people.

When I visited Aguatepec for the first time in Christmas 1992, there were only a few places to rent hammocks on the beach and one hotel, a Hindu-inspired place where people came to take meditation courses. When the Californian woman who built this first hotel arrived in Aguatepec with her two children in 1970, the place was almost inhabited, with a few travellers who visited sporadically.

Aguatepec has had a steadily increasing population growth in the last decades of the 20th century, but it seems like many peasant families who came from the 1950's up to the 80's are regarded, and regard themselves as natives or "owners" of the place. These people were poor and landless peasants who came because land was available, as a survival strategy.

Since 1990 there has appeared a variety of new tourist establishments, most of them *palapas*⁹ where they rent out hammocks, or bungalows/huts. Other establishments and houses of increasing standard and size, together with a few small hotels, have been built very close to the beach. There are probably nearly a hundred small restaurants, bars, cafes and tiny shops. The telephone line to the community was installed in the 2000, and the number of internet cafes has risen from one in 2001 to six in November 2005. There is also a new public health care centre, and on my last fieldtrip, in November 2005 a small library had been established.

The rehabilitation centre *Palapa Papaya* also has an internet connection, and their library, which primarily consists of used books donated by volunteers after they have finished their assignments, was officially opened in July 1995.

In the most recent development of the community of Aguatepec, since the 1990s, people with disabilities have continuously been present and to an increasing degree active and engaged, a fact that seems due mainly to the presence and influence of *Palapa Papaya*. Certainly people with disabilities have always existed, but they have not always had the chance to participate openly in social life, or even survive, something which is now changing.

⁸ Indigenas: indigenous language speaking people

⁹ Palapas: palm huts without walls.

Historic introduction to Palapa Papaya

Palapa Papaya was officially established in 1984 by the American natural doctor and *curandero*¹⁰, Palmer Brown. During a period in the 70s he had lived and worked in the area, and had become aware of the many unmet needs of the population. This was especially with regard to health care, and he therefore came back in the 80s with a mission to serve some of these needs. As a doctor, "Pablito" Brown was especially occupied with children, and he came to care for sick or disabled and often orphaned children for longer periods of time, before he decided to open a joint institution, an orphanage and a school. In January 1984 the Swede Teresa Andreasson arrived as a volunteer, and she decided to stay together with three more volunteers, to help Pablito in his work.

Initially Teresa had come to Aguatepec looking for Pablo Brown, after some friends in San Francisco had told her about him and his mission. From the age of fifteen she had worked with disabled people in Sweden.

In the autumn of 1984 the institution Palapa Papaya was officially founded, and several children came to stay. Some stayed only for a shorter period, while others moved in on a permanent basis. Of these some were orphans, or they had families who where not able or willing to provide for them. A few of these, who are now youngsters, still live in Palapa. In the beginning Pablito, Teresa and the three volunteers only had two small huts, divided by a palm-covered corridor. One hut contained the kitchen, the other a dormitory and living room for everybody. The palm corridor was much used for play and therapy, and it was also where people from the nearby communities could come to seek medical help and advice.

Pablito used herbs as medicine, one of them marijuana. For children and adults this would function as a pain reliever.

This was probably the main reason why the Mexican government and regional security forces at the outset did not look kindly at the institution. Police officers came to look for Pablo several times, but he hid, and avoided them. Then, in 1986, Pablo, suddenly fell ill and died at the hospital of Oaxaca. It happened so quickly that everybody was taken by surprise, and people in the village, together with the centre's young patients, started to create alternative explanations to Pablo's sudden death. One of these stories alleged that Pablo had been caught by the police and had been beaten so severely that he died of the injuries. Teresa Andreasson, who sat beside her friend's deathbed, has however discredited this version, and I choose to believe in her, and the official version.

At this point Palapa Papaya could well have died with him, but Teresa was not willing to give up, and she had promised Pablito to continue the work.

¹⁰ Curandero: healer.

Pablo had seen that children with disabilities seemed more likely to be abandoned by their parents than other children. Teresa therefore specialized in physical and social rehabilitation of children with disabilities. Several new volunteers joined in the work, and with them Palapa slowly grew and expanded, with the result that they could help more people. In the beginning Swedish, American and Canadian volunteers dominated, and economic funding came mainly from organizations in these countries. From 1991 the staff received some training from the governmental organisation CREE (Centre for Rehabilitation and Special Education) in Oaxaca City, though they had already established contacts with foreign and national medical specialists and rehabilitation therapists.

Since March 2000 there has been an increase in Japanese volunteers at Palapa Playa, as the governmental organisation, Japan International Cooperation Agency (JICA), has paid for professional volunteers to stay for a period of two years. In this manner, both the volunteers and Palapa Papaya are sponsored by JICA. They also support the centre in other ways, for example paying for constructional work. However, funding keeps coming in from a variety of sources, both private and governmental; national and international.

Geographic location

Aguatepec seems to be a rather slender village physically, but that is only the part located by the seaside. The village also consists of other parts that are not directly exposed to the sea. In total, the village has around a thousand permanent inhabitants, living in three clusters; *Casa Blanca*; the richest neighbourhood, at the western part of the beach, *Arollo 3*; the poorest part with very little infrastructure up along the dry lagoon north of the beach and furthest away from the tourist establishments, and then *Las Piñas*; a small area just east of the beach and up towards the new *Ocean University*. *Palapa Papaya* is located in the middle of these neighbourhoods, behind the beach and the tourist establishments, with *Casa Blanca* to the west and *Las Piñas* to the east, "Arollo 3" is north-west and the hillside north-east has newly been baptised *Los Altos*.

Palapa Papaya is a small community in the community, and the rehabilitation centre is made up by a cluster of one floor houses and huts. Formerly the centre's buildings were even simpler, but after the hurricane Paulina destroyed many of the buildings in October 1997, they had to restore important parts, which were then given solid floors, elevated from the ground. The number of houses and huts varies from 20 to 30, depending on how detailed one counts.

Paths make the whole area of the centre accessible to wheelchair users. All but two buildings have one floor only, and the ones that are built on pillars or elevated from the ground by foundation have ramps of cement or wood, which make them accessible for all.

The small library and study house are located in the inner edge of the area of the centre. To move from there to the therapy area, one passes a small white chapel, dedicated to the centre's founder, which is protected and decorated by an image of the Virgin of Guadalupe. The therapy area is a new construction, where five main buildings are sharing a foundation, with open spaces, as small streets, between them. The largest building houses a gym used both for individual and common therapy sessions, meetings, and play. Outsiders to the centre may also employ the gym, paying a small maintenance fee of five or ten pesos, but that happens rarely. The other four buildings houses offices used for personal consults and training. This is where the four therapists are based during the day. The doctor's consultancy is normally open only one hour in the morning, before the doctor, who lives inside the area, goes to his private office in the town of *Comintla*. There is also a common bathroom and two large rooms with bathrooms where temporal patients can come to live.

Coming down from the therapy area one arrives at *el corredor de palmas*¹¹ which is the centre's oldest construction. It houses three solid buildings where workers at the centre live, occasionally together with own visitors or temporal patients. On one end of the paved corridor lives the centre's coordinator for volunteers, Tomas, who is himself a wheelchair user. At the other end of the corridor lives Tia Amelia, the centre's most senior cook, a widow with three grownup sons who live by themselves now. Next to Tia Amelia's house is another, with the entrance on the other side. The centre's main artisan, Tito, also a wheelchair user, lives there together with his teenage daughter Dolores, his niece Paloma, and his old mother.

The next house one comes to, which stands as a little sugar cube in the middle of everything, is *la oficina*: the office. The back wall outside the building serves as a canvas for a colourful mural painting, which is a reproduction of a postcard made by one of the children with disability who lived at the centre. Two secretaries work in the office during the day, while other workers, patients or visitors, often will employ its facilities in the evenings.

Diagonally from the office is the kitchen, which I perceive as the centre's heart. The kitchen is a rectangular wooden hut, with lots of open gaps between the grey boards, which works as ventilation. The two doors to the kitchen are normally open, and four to six women work here permanently. There is regular activity going on in the kitchen from about half past six in the morning until ten o'clock at night. The regular activity consists of cooking, washing, planning, preparations, and a lot of talking. The bustle in the kitchen comes from and seems to attract a lot of the people at the centre. Patients, workers,

¹¹ Palm corridors are typical outside of houses in this region. The construction consists of wooden frames, as for a house, but without any walls, other than the front wall of the house, which can be made of cement, or adobe bricks, normally painted white, yellow or pastel colours. The "corridor" is the open space under the palm covered roof made on top of the frame, which provide precious shadow from the sun, and natural ventilation. The corridor might have solid floors, or just earth or sand. Normally there is at least one hammock there, and a few chairs and a table, and if it is a private home the family often eat their meals outside during the day.

children and adults stop by the kitchen on their way to other activities, and for some the kitchen in itself is the destination. The cooks are occupied with their work, but they also chat, listen to the radio, discuss local happenings, and provide a free area where the centre's actors can launch topics of their concern.

From the office another path goes to *el paraíso*, the building complex of the youngsters with severe disabilities. These five youngsters are the only permanent patients of the centre. This building is also elevated from the ground, to protect it from flooding. There are five large rooms built together, and the youngsters live in two of them, where they have their beds, which for some are enclosed to protect the persons from falling. The rooms also contain a few chairs primarily used by caretakers and visitors, a *casetera*; a tape-player, a television, and a special computer which the leaders have got high hopes for, but which did not function for the time I was there. Then there are also an ample bathroom and two more *habitaciones*, rooms, for living. Mari, the cook, lives in one together with two of her children. One of them has a progressive muscular disease, and sits in a wheelchair. The last room was used for visitors while I was there for my first fieldwork, but on my last trip four young women between the ages 15 and 30, had moved into the two rooms, Mari's son Mateo had died, and she and her daughter had moved into Tito's old room, next to the palm covered corridor. Tito had moved to his own house in another part of Aguatepec, and his daughter and niece had migrated to California, where they had joined Paloma's parents; that is Tito's brother and his wife.

The base of *el paraíso* also has a generous open space, a *corridor*, where the permanent patients spend some of their time. This space was also used as working place for the artisans during my first fieldwork, which provided quite a lot of activity. To me this seemed generally positive, particularly for the permanent patients who did not have a lot of activities during normal days. Towards the end of my first fieldwork, they nonetheless opened up a pure artisans' area, which consists of a shop and a workshop, built of wood, on high pillars above the ground. It was located as far away as possible from the old work area. It has clearly brought advantages to the artisans, who can now leave all their equipments and products on the site, instead of storing it, and putting up the workshop every day, as they did previously. The shop also gives them pride, and generates more income than before, when most of their products were sold to secondary merchants.

Daily routines at Palapa Papaya

Palapa Papaya started out as a children's home and school in 1984, but after a decade they had to a large degree left that institutional model. They realized that as an orphanage, they had limited opportunity to influence the surrounding communities, and they could only reach a very limited number of children.

Instead they increasingly opened up to the outside community, and they now believe that children should be with their families and in their communities. The priority now was to support persons with disabilities as well as families and communities with practical information, knowledge and training in order for them to be better prepared for, and able to support themselves and other community members with disabilities.

As a resource centre, Palapa Papaya now tries to engage and show parents and families how they themselves can work with and support their children, with or without special needs. The decision to support and strengthen whole families and communities where persons with disabilities live, has nevertheless also given rise to a certain discontent in the village of Aguatepec. Some villagers, backed by families who have previously been loosely related to the centre, feel that it is unfair that whole families now are supported. They are caught up in the institutional model of rehabilitation that ruled in Palapa Papaya until the 90s. Since that time Palapa Papaya has changed and developed both their internal and their external policies during their 20 years of existence. They have received incentives, such as the general model of Community Based Rehabilitation (WHO), and the experiences from the pilot project PROJIMO¹², carried out in the northwest of Mexico since 1982, and certainly also from volunteers.

The changes beginning in the early 90s meant starting an out-reach model, which some years later was expanded to whole communities. They are to an increasing degree engaging and cooperating with authorities and volunteers from the actual communities who want to become community rehabilitation workers.

Although the emphasis now seems to be given to Community Based Rehabilitation (CBR), the centre also works in line with the earlier paradigm, as an institution, and hence functions as a resource centre and a show-case for people who are interested in disability.

The rehabilitation centre has a permanent staff of 33 persons: 18 women and 15 men. In the staff there are 7 persons with disabilities: 1 woman and 6 men. Of the staff as a whole, 24 employees have more than five years of experience at the centre.

30 people live more or less permanently at the centre; of these 20 are children and youngsters, 5 of them have serious disabilities, while 4 have other disabilities. There are 10 adults; of which 3 have a disability. In addition 20 children, who have parents working at the centre, and one adult with disability, come to eat at the centre, or receive practical or economic help for schooling.

There are normally approximately 15 volunteers participating in the different activities at the centre. Half of these are usually Mexican, while half are foreigners. The volunteers are normally young people,

¹² Proyecto PROJIMO came into being in 1980 as an appendix of the general community health project "Piactla", both initially localised in the same community in the state of Sinaloa. P.R.O.J.I.M.O. stands for Programa de Rehabilitación Organizado por Jovenes Incapacitados de México Occidental, Rehabilitation Program Organised by Disabled Youth in West Mexico .

and most of them live at the centre. Visitors, who can be temporal patients, relatives, or students, may also stop by, so there may be up to 50 persons for dinner on a normal day.

The centre also receives some professional, often international, health workers, who come and stay at the centre to train the staff or perform intensive medical treatment of patients for short periods of time.

The Japanese volunteers, as well as some Swedish, have a special position as they are predominantly professionals, who are paid from institutions in their own countries to work. They often stay for a longer period; that is one or two years, while the regular independent volunteers' stay is 6 months.

Every week there are several meetings at Palapa Papaya. On Tuesday mornings most adult workers and voluntaries attend the *asamblea general*, where the coordinators for the different work areas inform about their activities and plans, and the general coordinators speak about centre policies, activities and agreements. At the first assembly I attended, for example, I informed about the joint proposal of my stay; that I would serve as a regular *voluntario*, but at the same time I would be gathering information for my master's thesis in Social Anthropology, and that I therefore hoped to get to know the centre and its' people thoroughly.

The assembly is open to all. The disabled people who attend are co-workers, from most of the work areas at the centre; coordination (1), kitchen (1), special needs (2) and garden/horticulture (1). In addition two of the artisans, who are disabled, often participate eagerly in the discussions.

Each work group has an internal meeting once a week and the coordinators of the groups also meet weekly in order to make plans and discuss internal questions. Finally the volunteers have a meeting once a week, normally during the afternoon on a workday, where they plan work activities and discuss any questions related to their stay.

After my main fieldwork stay, Palapa Papaya also started a children's assembly, where all the children and youngsters affiliated to the centre meet and discuss their interests regularly. The internal patients, who are all youngsters, also attend this meeting together with a worker they know, who understands their signs, and therefore can speak their case. All children, disabled or not, who can speak for their own may, and should, attend. Children and youngsters who stay at the centre temporarily for rehabilitation, may also attend the assembly. I had hoped to attend at least one of these assemblies during my second fieldwork in November 2005, to see how they worked, but I was not able to, because they were temporarily suspended to give room for special priorities. The Day of the Dead – *el Día de los Muertos* - which is the single most important celebration in the region, was rapidly approaching.

In the holiday, *la Octava de Muerte*, which last for one week in early November, some of the workers and their children, as well as some temporal patients may leave to visit their families outside of

Aguatepec. Following the holidays of 2005 Palapa Papaya was also arranging a popular annual sports competition simultaneously with a three-day-long mini camp with workshops for children and youngsters with disabilities from the region. Both these forthcoming activities occupied people's minds and planning capacity.

One group who met regularly were the ones in *Estimulación Temprana*, Early Intervention/Stimulation. The group consisted of up to 15 young children from 0 and 6 years old with different disabilities, and at least one family member, usually mother, who met in Palapa Papaya's gym once a week for training led by one of the centre's therapists. There they followed a common program which the parent should try to carry out with the child, who would sit or lie on a mat on the ground. The therapist also went around to every child to see how he or she was doing, and talk to the child and with the family member(s). After the session most of the participants eat in the circular *palapa*, the open hut used as refectory. The conversations between these families and staff, volunteers, patients and visitors are important for all, because the families can share experiences and get support and advice from different people on how to handle their situation. If a child needs medical intervention, members of the staff at the centre have *palanca*¹³ in relation to doctors, hospitals and financial supporters, which they can activate in order to help the person with disability and his and her family.

Some meetings were held with these parents only. There they were given special information about their children's disabilities, and explanations of the exercises that they were encouraged to employ also at home. The intentions were particularly explained to the fathers, who often could and did not accompany their children to the exercise sessions; and therefore might not understand the reasons for keeping on doing exercises with the child. The individual progress of a child might be slow, and often exercises are needed in order for the child's condition not to deteriorate. Both for persons with cerebral palsy and for those with polio sequels regular exercise is needed to hinder their limbs from stiffening. As a consequence of several meetings, parents of children with disabilities in the region organised and set up their own help- and interest group PAHIDOS, (Parents of Disabled Children in South Oaxaca), after they had met representatives of a parents' group, *Los Pipitos* from Nicaragua, and learned how they were working.

According to the centre's activity report of 2001, six of the children in this group learnt to walk during the year. Four parents later participated in the centre's local radio program, broadcasted once a week, where persons connected to the centre inform about issues concerning disability, health and social problems. One long-time resident at the centre, who is originally from the sierra, used to carry out

¹³ Beneficial contacts and networks, or effective social capital.

sessions in *Zapoteco*, her natural language, and the most common indigenous language in the region of Oaxaca. She has a child and a husband with disabilities.

The times of year when most activity and discussion between children and youngsters with and without disability take place, are probably during spring-camp after Easter and summer-camp in July. These are popular arrangements where young people from nearby communities, or from communities who apply CBR-projects in coordination with Palapa, are invited to participate. More than a hundred children under the age of 17 participate in these, and about two thirds of them have a disability. Workshops are held, in music, theatre, painting etcetera. Children who need extra help are aided by the volunteers who suspend their normal routine during these times, and extra helpers are also welcome in these periods. The young internal patients also participate in the camps, and seem to love this time as much as the visitors, as there is a lot of fun and activity going on, and it is a break from the routine.

Recently the centre has started to work more in this line, arranging "*mini-campamentos*" for children and youngsters with disabilities regularly, which seems to generate much joy and vitality amongst the participants, and at the centre as a whole. At the camps they get some of the effect of "the good old days", with joy, energy and friendships, but they are spared most of the suffering and longing of the old days, when many of the children interned at the orphanage were missing their families badly.

A flux of people

A person with disability who comes to Palapa Papaya for a short period of time is often required to bring a family member, who should help with daily chores. The helper should also attend their relative in some therapy sessions in order to learn techniques to be used when they go back home. In addition, the relatives take part in the daily and weekly activities of the centre. It is now rather normal that a person with disability, who comes in for intensive treatment for a short period of time, may not have co-patients with the exact same disability, or injury, and thus he or she does not form part of a natural patient group who meet for discussions and gatherings.

This is a contrast to "the old days" in the 80s, when a lot of children with disabilities lived together in Palapa Papaya for extensive periods of time. My friend and assistant Timo would present vivid and a bit nostalgic accounts of how much fun they had when the founder Pablito arranged competitions and games for the kids, where two and two were "matched" so they had the same level of disadvantage, or handicap, and then they were set up to "duel". Timo would run like a dog; that is on four legs, while his competitor José would run like a rabbit; using his arms and his buttock, and both techniques were efficient.

Both boys had the same sort of disability, namely polio sequels, and in their childhood both had their legs crumbled up. Later, when they were about ten years old, they were interned together in the same

room at a hospital in Oaxaca to undergo surgery to straighten out their stiffened legs. It was a long and arduous process which included a lot of suffering for the boys, and also for their families. Their family's support seems to have played an essential part in their rehabilitation and identity formation. During the months of hospitalisation, away from their family, someone from Timo's family managed to travel the long way to visit the boys once a week, despite the fact that the family faced extreme poverty at the time. José's family, who was far better off economically, did not manage to organize such visits regularly. When the boys returned to the community, their suffering was still not ended, because both came with their legs in a plaster cast, which they had to keep on for half a year, in order for their legs to grow as required. In the intense heat of the coast this must have been a question of tremendous patience for the boys, and equally for their parents. Both boys were crying, wanting to open and take off their cast. Timo's father could not stop his son from making holes where he put in sticks to rub his skin, which was itching, but he told his boy to be patient, and that it was for his own good. José's mother, whose husband had left her and their children, leaving her to drown her sorrows in alcohol, did not stand her youngest boy's crying and insistence in taking off his cast, and during a party she and one of José's elder brothers ripped it off. The doctors in Oaxaca were angry when they got to see this, but they nevertheless plastered the boy up once again, warning the family that they had to leave it on. After a while the cast was removed once again, and now it was not put on any more. I do not know if these actions and results are what still haunt José, I only see that the two former friends have developed very differently. Currently they hardly speak to each other anymore, although they have a lot of painfully embodied childhood memories in common. When I first saw José in the little shop that he owns and runs, I thought he was an amputee. Though I asked Timo, and he told me that his old friend had just grown very little. José is always sitting in his wheelchair in a somewhat horizontal position, covering his body under white blankets. Someone is usually accompanying him; his wife and her children, some of his brothers or workers, or some of the community's beer-hounds. José is chubby and often smiling, but he has a very hard time moving around, and someone use to push his wheelchair. Timo, on the other hand is poor economically, he lacks a job or a student position, but his health is generally good. He needs crutches and leg-braces for walking, and uses his wheelchair only for recurring long distances, or for playing sports.

These days, as many temporal patients do not have the advantage of the peer-group, they do nonetheless seem to be approached by one of the centre's workers who has gone through rehabilitation due to a similar condition earlier, for example due to polio sequels or spine injury. If it is possible the temporal patient may be installed to live next to one of the centre's rehabilitated persons, as was the case of Jimador. He was a man in his late thirties, who had just suffered spinal injuries in a traffic accident. He came in for intensive treatment which lasted for about a month, accompanied by his wife and his mother. (His children were placed temporally with their mother's sister.) The three adults were installed to live next

to one of the centre's coordinators, Tomas, who had an accident several years ago, with similar injuries, and who were indeed contributing to give Jimador and his family more optimism for the future with his own history and not least his current work and living as example.

One immediately sees that there are several persons with disabilities at the centre, but most of them actually work here, or in affiliation to the centre. These persons have formerly been patients at the centre for a longer or shorter period of time. In addition there are also young adults, who more or less have grown up as internal patients at the centre, who are now married and work in the village.

None of these are actually treated as 'patients', and although they use the label "disabled" on themselves, as well as most other people do, I consider most of them as more "abled" than disabled, in their settings. The label disabled has been promoted both through national campaigns, as in television-ads, and regionally and locally through NGOs such as Palapa Papaya. "Disabled" is emphasized as positive compared to "sick", which was the category persons with disability fell under formerly, and which many people without education still use. A reason for emphasising disability over sickness is to get a focus on rehabilitation and adaptation instead of miraculous cures.

All the persons mentioned have gone through rehabilitation programmes, which for many of them included surgical operations, training, conditioning of the physical environment, and equipping. The results of the rehabilitation varies a great deal, certainly according to the type of disability one have, but maybe even more so according to one's spirit and motivation for going through an arduous programme, and the support of the family and community. During fieldwork I saw many examples of people with the same diagnosis, which resulted in very different actual conditions. The same diagnosis can have innumerable variations in severity, but what seems just as important for the actual lives of people are their own attitude, and the people in their surroundings' attitude towards them, as the example of Timo and José showed.

When I came down to Palapa Papaya for my second fieldwork in November 2005, I soon noticed changes in the environment and most visibly in the resident population. Two teenage boys with quite severe disabilities had died, two teenage girls without disability had migrated to the USA, two households had moved out of the centre's area and into new settlements in the village, and several new persons had moved inside the centre. In the organisation of the centre there were many changes as well. Most notably *la mera mera*; the main coordinator, who had headed the centre for almost twenty years, and who had been present from the beginning, had withdrawn significantly from the centre, moving out; although she continues supporting, communicating and visiting the centre. The CBR-projects were expanding, encompassing two new communities, and also a community which they had formerly given up because of lack of local support.

Five new long-term residents at the centre also represented a considerable change in the centre's environment. These were all young adults in the age between 15 and 30 – four girls and one boy – who had different physical disabilities. They were accomplishing different activities during the day, which included personal rehabilitation and education, primary school for the youngest, and work at the centre, eventually combined with higher education, carried out primarily on individual level at the centre. These youngsters also organised and participated in a one-year leadership course for over 20 other youngsters with disabilities in the region, where the aim was to share experiences and develop personal and social skills and abilities. The friendship and integration within this group seemed very strong and positive, and I heard statements that made it evident that they now had a new group identity. Some of these youngsters had never been or wanted to be much in touch with other people with disability, and I believe this attitude makes them more vulnerable to – often silent – discrimination. As strangers to Aguatepec they also felt that the place provided a lot of freedom, compared to their home towns.

Then there was Burt, a North American ex-volunteer to Palapa Papaya, who is blind and has settled in the village. He often comes by the centre for a meal and a chat, and with his experience he is able to help people at the centre in different ways, for example in reading Braille, and as a general consultant.

Very close to the centre, just by the artisan Garp's house, Oscar – a young man from the City of Mexico – came to live, earning his life renting out internet access. Oscar had some sort of disability, but he was not open about it. He seemed to have a muscular deficiency, or perhaps a light cerebral palsy, but what was more important was that he was great with computers. Although he clearly had some problems controlling his limbs, he was not described, nor described him self as disabled, at least not to my ears. Like Burt, he also tends to drop by Palapa Papaya for a meal and a chat, and he is often hired to come and fix the computers at the centre. (He was the one who would help me save the internal memory of my laptop when it suddenly broke down in the middle of my fieldwork.)

Thus Palapa Papaya seems to provide a safe meeting place for people with disabilities in the region. Still several people with disabilities in the community do not go there, and many of these don't meet each other as disabled persons, but only accidentally in different situations. However, it seems like most people with a disability or a health problem in Aguatepec and surrounding communities have received support by the centre at some stage of their life.

The five permanent patients, who are all young people in their late teens, have an almost imperative status as patients and disabled. From the outside they seem to have no possibility to escape these terms, nevertheless they are just labelled "the youngsters" at the centre. Due to the severity of their impairments, with limited abilities to communicate, they hardly have a say about the services given at the centre, which

I indeed think are relatively good. Although they have limited possibility of proposing ideas, their views are considered when possible, and as they hear and comprehend the meaning of words, the category “youngster” is certainly emphasising other parts of their identity than the category “disabled” would do.

What is central, though, is that these youngsters do not have an alternative to living in Palapa Papaya, because their families have given them up since they were infants, and returning to them is not an option, although some of them tend to be dreaming about that.

These youngsters live and stay together every day, and therefore they meet almost constantly. Nonetheless, they do have different interests, needs and *caprichos*, that are fancies, and each one of them is to a large degree comforted.

Los jovenes, or “the youngsters” normally eat by themselves, prior to everyone else at Palapa Papaya, so they do not meet other people more than briefly in relation to the meals. Nonetheless, some of them prefer to stay in the refectory area when they are finished eating. Sara, who has got cerebral palsy, in particular likes to just hang out close to the kitchen, and have a chat with someone. A “chat” with Sara normally consists of asking her about her day and her well-being, and she will answer with facial gestures, which are easy to understand. Then she might introduce a theme, pointing at some of the pictures in a “pictionary” that she has in front of her, on a small permanent table on her wheelchair.

Amado was the only interned patient who had family members at the centre, and even though he lives and sleeps together with the other internal patients, he will also have some family life, for example following the meals, and he loves spending time with his sister and cousin. He can not express his happiness verbally, but it is impossible not to see his joy when he stays with his sister, because then he laughs and smiles and communicates well-being with all his body.

During “normal time” in Palapa there is also quite a lot of flexibility and change in the environment, due to new patients, volunteers and visitors coming and going, which enables new friendships and communication to emerge. Though there are also many departures, which are often sad; but this is all part of the setting, and people who live or work in Palapa, including patients, have become used to this feature, and it does not seem to result in personal insecurity. I see the centre’s flexibility and change more as a “win-win-game”; all participants on the whole – that is generally – come out benefited, even though the flux might perhaps generate a somewhat instrumental attitude to friendship.

The work day

The official work day for the majority of employees at Palapa Papaya starts around eight in the morning.

Before that one can stop by the kitchen for a cup of coffee and a sugar bread or cookie, and clearly the kitchen staff starts their day earlier. Take Mari: She is a single mother in the middle of her 40s who

now lives together with two of her children, both at the brink of their teens. One of them, Mateo, has a muscular disease, which slowly takes control over his body. His mother has to wake up several times in the night to turn him around, because he is unable to do that himself any more. I'm not sure when Mari gets up, but it can not be any later than six. Fortunately she has the help of her daughter Dalila. Dalila seems always to be there for Mateo, walking him around inside the centre's area, and occasionally in the village. Though, before eight in the morning she goes to school. Mateo does not go to school any more, so he spends the day at the centre, mostly inside the kitchen, with his mother and all the other women who are gossiping while preparing food, or he hides in *Tia Amelia's* room, watching television.

From eight to ten everybody goes to their work area, and for most of the volunteers that changes every day.

The women in the permanent staff guide the volunteers' work. The volunteers are normally given easy tasks, like washing, disinfecting and cutting vegetables (tomatoes, cucumbers, salads, avocados, *jicamas*, *chayotes*, fruits, *chiles*, etc.) which the cooks prepare in different ways. The food at Palapa Papaya is surprisingly tasty, and healthy, although the staple foods remain the same for all meals. Some volunteers and workers do grow tired of that, and prefer to cook some meals for themselves, or eat at a restaurant.

Most vegetables are grown on the centre's own land, organically, or bought from local farmers. That's the issue with the two most substantial staple foods, namely maize and beans. Just as every household in the region, Palapa Papaya stores large amounts of dried beans, which the *cocineras* prepare and serve every day. *Los frijoles* – the beans – need a lot of cooking. Normally they are washed and put in casseroles of water every night, and cooked – with salt and onions – in the morning.

At approximately ten, *las cocineras* bring out the food for lunch break, *el almuerzo*. There are always one or two huge casseroles with *frijoles*, a big basket of maize tortillas which are brought to the centre every morning by the local *tortillero*, a gracious one-armed man who delivers tortillas around in the village from his transport-bicycle. Then they always serve a "main" plate, often eggs in some variation; fried, revolved, or in tomato salsa, plus a variation of vegetables, fried or in a stew. On the side one or two spicy salsas goes to accompany, and often also a fresh salad. To drink there is some sort of homemade fruit-mix, for example lemonade, *agua de Jamaica*, *agua de melon*, or *agua de tamarindo*, according to the season and the cooks' fancy.

Lunch is served from ten to eleven. In these hours people from all the work areas mingle in the two *comedores* outside the kitchen. The food is placed on tables outside the kitchen, and everybody must serve themselves; though people who could need a hand most certainly get it. Both people with and without disabilities help each other out.

For example I, as a more or less able-bodied volunteer, often bring an extra glass of lemonade for my friend Garp, who sits in a wheelchair, and I know it is more difficult for him to balance a glass, though not at all impossible. He might or might not ask for assistance; because he can easily do it by himself if a *voluntario* is not around. It just takes him an extra turn. Then I might serve myself some of his tortillas, or I can ask him to bring some extras, if I see him serving himself.

I get the impression that it is especially easy to ask the volunteers for help with small or everyday matters, like carrying an extra glass. Services like that do not cost a thing, they are not demanding, and most people are happy to do them. The volunteers are here because they want to, and not because they are obliged to in order to earn money. The permanent workers, on the other hand, would perhaps get annoyed if they were asked to do things they know, and probably consider that persons with disability should do themselves. There might very well be an aspect of liberation pedagogy or theory to this as well, which many volunteers might not reflect upon in their eager to “help”. Anyway, for more serious matters, like cleansing severe injuries, or performing therapeutic exercises, the persons who need help have to ask one of the permanent workers, or a volunteer with professional skills in health service.

During mealtimes most persons who have got family members at the centre, seem to prefer to eat together with them, but according to their work tasks and individuality, where their eventual disability also is part, they can also eat with other people. Tito, the centre’s carpentry master, likes to eat together with his daughter Dolores, but if she is not present, or if she sits together with a bunch of youngsters, he will sit another place. Nine-year-old Aurora, who has Down’s syndrome, would probably like to eat peacefully with her mother, but that is normally not possible. Aurora has five younger brothers and a dad who can also need a helping hand due to his disability. Therefore the teenager often eats together with the volunteers, who are usually fairly patient in trying to talk with her. Although Aurora has difficulties with speech, she is a very sociable girl, who tries to communicate with people.

If Auroras mother Alexandra, who works both in the centre’s kitchen and in a restaurant in the village, has the time to sit down with her oldest daughter, she is also more or less obliged to try to teach her “good manners”, and neither mother nor daughter seem to like that situation, and therefore they seem to avoid it in public. Another teenager, Mateo, does not accept to eat together with, or even be served by anyone but his mother or sister. I think that the different tendencies and preferences have more to do with the individuality or personality of each person, than his or her eventual disability. Mateo is not very talkative, he does not “lend himself out” to talk; *no se presta para hablar*. His older brother, though, who suffered the same disease as Mateo, was very open and talkative, I am told. One might think it is strange that two brothers with the same inherited disease, and “the same” upbringing should develop quite opposite personal characteristics, but they did. The oldest brother, Felix, might have been likely to experience more hope from his surroundings as well as from himself, and the youngest one; Mateo, who

saw his brother fight but slowly wither and die, and with him probably also some of his own and his family's hopes, chose to withdraw. "He let in the sad part", his mother Mari told me in November 2005, half a year after Mateo had died.

Often one of the cooks takes pride in serving the main plate, though another reason to serve the food might be to distribute it evenly. This is not done consequently at all meals, but when the cooks seem to have time and motivation to do it.

Food security might also be a reason why the permanent patients, who have got special needs when it comes to diet or eating, normally come to eat prior to the rest. One can also suggest that it is good for them to eat quietly, and without the interference and pressure from the rest, who use "manners" while eating. Or from the other point of view; that it is more comfortable for the capable majority to eat without any disturbing presence from the ones with special needs, who can not use the same manners, due to physical or mental impairment.

Manners are clearly culturally relative. High class Mexicans regard some typically lower class Mexican ways of eating which are practised at the centre as "bad". At the centre, as in regular low-income households one does normally not use a knife and fork for eating, but only a fork. Then you use the *tortillas* as a combined "means" and "goal", that is; you first use them as utensils for eating and then you eat them, alternatively you can make your own *tacos* by putting all sorts of food stuff, for example rice, vegetables, eggs or meat, and salsa inside the tortilla(s). It is also relatively normal using a tortilla to clean one's hands, but this practise is definitively not approved by the higher classes. I remember hearing some *fresas*¹⁴ say that seeing someone clean their hands with a *tortilla* is totally disgusting. To me, in this context, it soon became – and felt – quite normal, though.

The persons with physical impairments who work at the centre, do not have any problems with manners, but the internal patients with severe disabilities do. For some this is due to large physical problems, like severe cerebral palsy which impede them from eating alone, while others who have got developmental problems, as autism or psychological injuries from birth, do eat efficiently on their own, but without caring much about manners. Some need stewed food to be able to digest it, and for all; their eventual medicines are crushed and put into the food.

After lunch everyone goes back to their work area, where they continue their work. In the garden, for example, there are a lot of things to do: Much of the tasks here require hard labour, since the soil is very dry and hard, especially outside of the rain season. The only permanent worker here is Abraham, a young man with polio sequels, who uses a bicycle to get around faster than his gait will bring him. He is the leader of this area and the one planning the work. Abraham seems always to be smiling and ready for

¹⁴ *Fresa*; literally 'strawberry', but as a "mexicanismo", a modern Mexican term; it means snob, or a person who thinks himself, or herself, to be very special and important.

chatting and joking, though he is also a respectable family man, and the father of two small children. In the garden Abraham has made some beds for vegetables, including one-metre high cases, which have easy accessibility also for wheelchair users.

Then there is Hiroki, a young Japanese man. He is a professional agronomist, and is sent out to Palapa Papaya by JICA for two years. He mostly runs his own projects, and works alongside with Abraham. Hiroki works hard and independently, every day, for example preparing the soil to plant there. Due to the lack of specialized equipment, he does it the old Japanese way, just piecing the earth to dust, while using a lot of muscular force.

Normally there are also a couple of volunteers working in the garden every day.

Abraham tends to give the volunteers an easy work day, mostly with making recycled paper. Most of the work is done under a roof, which protects everybody from the sun which is very intense during work hours. The work is not very hard, but it needs to be done. Hiroki, on the other side, tends to let the volunteers suffer a little bit. When one comes under his control one will be certain to get some blisters.

From 14 to 15 there is dinner; *la comida*. This is normally rice with some vegetables, herbs or spices. *Frijoles*, as always, salsas, *tortillas*, and a main plate, made of fish, meat, eggs, or just fried vegetables, plus some sort of natural fruit-beverage.

Like always, the youngsters with special needs come there first. The workers in the special needs area may eat at the same time as these youngsters, but they normally wait until the youngsters are finished and are brought back to their house. This is partly a practical solution, as the workers use this time to feed or help the patients. Then the women from the office usually go to eat, and people from the different areas mingle in, the therapists, the gardeners, the chauffeurs, the caretakers from “special needs”, eventually the coordinators, the carpenters and maintainer’s staff plus the artisans. These latter groups – (carpenters, maintainers and artisans) who are all men – often join each other in the smallest rectangular dining room. Many boys from the age of eight and older also seem to prefer this smaller *palapa* behind the kitchen to the main one, which is circular and located right outside the kitchen. This is where most women and smaller children normally eat.

By dinnertime all the children return from school, and the ones who live at Palapa Papaya, or have parents who work here, usually come to eat at the centre. The preschool kids use to eat together with their family, or with their mothers and the kids from school differ in their preferences. Some eat with their family, a sibling, or a friend, or just anyone, because everybody knows each other.

Occasionally some of the local fishermen donate their fish to the centre, especially near big holidays or celebrations. It certainly depends on their catch, but near the holidays of Christmas and Easter it is certain that there will come in fish. On January 6th (2002) – on Holy Three Kings’ Day – the first fishermen

to come with some giant *atunes*; tuna-fish, were Jacob, one of my informants' in-law uncles and a friend of his. They arrived in the morning, so the fish was rapidly cleansed and richly prepared for dinner by the cooks. After dinner some other fishermen came to donate loads of *palometa*, a more regular, but tasty fish. The cooks who were still present, the centre's driver, a couple of visitors with and without disabilities, and I as the only available *voluntario* – all women – joined forces to cleanse all the fish. The dish-washing area was changed into a fish-washing area, becoming a magnet for mosquitoes for a little while. Afterwards everybody who wanted was given bags of fish to bring home. In the afternoon I could see people with bags of fish out in the village, looking for a refrigerator to get it stored. For the fishermen this day seemed as a perfect time to give away fish; Holy Three Kings' Day is symbolically significant for all Christians, and traditionally this is the day when Mexican children receive their Christmas gifts, as symbol of the gifts that the baby Jesus was given by the holy three kings, according to the Bible. Fish is also important symbolically in religion. What is also at stake is the freshness of the fish: The fishermen must get rid of the fish quickly; they must sell it, or give it away, as no big freezer or factory exists locally. Giving donations certainly bestow the fishermen with goodwill both from the centre and from the community as a whole, as it soon will be talked about and acknowledged by the general population in the village. Most fishermen will also have some connection with the centre; they may have a family member or friend who has received support here on some occasion. Señor Jacob, who came with the first donation on this occasion, has at least two nephews who had received or were receiving medical and social support from the centre. The very same fisherman was later elected *presidente* of the village.

The artisans' workshop is usually more crowded after dinner than before. In the morning there are just a couple of men working there, making wooden toys of their own design, and sometimes a couple of volunteers helping them. The volunteers might be allowed to make the same things as the artisans, which will later be sold from shops in Aguatepec, and soon also from Palapa Papaya's own shop, but the main tasks volunteers get in this area is cutting and decorating greeting cards and envelopes out of recycled paper. The artisans are paid per piece they make, which is their only steady source of income, and they prefer to terminate whole pieces instead of decorating *chingaderas*, unimportant things, as paper. Some of the paper cards are sold as well, but it seems that most of this production is used for writing cards and letters to organisations and persons who support the centre, in different ways.

The reason that this area is more crowded after lunch, is that some of the youngsters who attend secondary school during the day, and who live at the centre, or have some other affiliation, now come and work at the artisans' workshop. Here they are able to gain some pesos per piece they make, something that is an almost unique opportunity to gain money for youngsters in this area outside of the tourist season.

While I volunteered at Palapa Papaya, there was a lack of staff in the area of special needs' care. Therefore all the regular volunteers were asked to spend one additional afternoon per week with the youngsters, and everybody accepted that. On my afternoons I used to take one of the youngsters out for a walk. Most often the one happened to be Sara, who always appreciated, and often insisted on, a walk in the village. We would most often go to the little chapel, from where we had an excellent view of people's interactions on the main road. Then we would go to a private house to buy some homemade frozen fruit drinks which Sara was able to eat in a quite impressive and independent manner.

However, it was only after Sara and I had gone to this house several times that I learned to know, from people in the main staff at Palapa Papaya, that the son in the house Felipe, an attractive guy in his twenties, used to be Sara's boyfriend. I was surprised, but indeed happily. Sara is a very sweet girl; she is sensitive, outgoing, laughs easily and seems to be quite open minded. Also I think that it is significant for her to have – and even just having had – a boyfriend. Though, their relationship would have been challenging in the long run. Sara has cerebral palsy, and she has not learnt to walk, nor talk, though I believe she would have had the capacity to do so, but that it would have required an enormous amount of stimuli-training by her near family, or by professionals. Then again her family would probably have had to pay for intensive training, or tried to persuade the professionals in other ways. Unfortunately they gave up on her almost from the start, and she was placed at the centre (orphanage) when she was three years old, and seriously malnourished. Later her mother died and her father was an alcoholic absolutely unable to provide for her.

Felipe, her ex-boyfriend, had been working at the centre for some time, doing his social service, and this was the context of their relationship. Some time later he had gotten a new girlfriend, a North American, who has given him his second child. His firstborn daughter, whose mother is from the neighbouring village, already lived with Felipe's mother and his younger sisters. His mother heads her own household, and she seems to survive well on small businesses that she manages from her home. When Sara and I visited the household to buy sorbets the daughters in the family were often teasing Sara and addressing her as *cuñada*; sister-in-law, something both parties seemed to enjoy.

From six to seven in the night there is supper, or *cena* in Palapa Papaya. This meal normally consists of something similar to lunch and dinner, but with *pan dulce* for desert. There are normally less people coming for this meal. The workers and volunteers who do not live at the centre usually eat in their homes at nights, as do their children. As mentioned, many volunteers often prefer to cook something on their own, as a variation to the normal beans, rice and tortillas, or they can go to a restaurant at the beach. This happens eventually in the nights. The volunteers have a nice kitchen and *comedor*, inside of Palapa

Papaya, in their living area, which is newly constructed from the Japanese governmental agency JICA's financial support, in a somewhat Japanese style, on the edge of the centre's area. From time to time some of the youngsters with special needs are brought to hang out in this area in the night, some of the workers or temporal patients might also drop by, as well as private visitors. At times visitors to the centre, for example ex-patients or therapists, come to live in this area for a smaller period of time (from a week to three months).

In the night most people from the centre have time off, and after a while the group of volunteers where I was part, started an own hammock workshop on our spare time. Irma, one of the cooks at Palapa Papaya, who had learned how to knit hammocks while this was an integrated part of the centre's production line, voluntarily taught the volunteers how to do it. It was a lot of fun in the start; we hammocked in our entire spare time, occasionally after lunch, and a lot in the nights. After a while it became more boring, though, because it really takes a lot of time, especially if you want a big and luxurious hammock; but fortunately everybody were able to finish, with the help of some workers, patients and friends.

Almost every week, and especially around full-moon, people make *fogatas* – fires – on the beach of Aguatepec. Anybody who see, or hear about a *fogata*, can attend if, and it is normally like a small party. Often there are musicians, especially drummers, or guitarists, and people sing. These *fogatas* are often made by some of the *semilocals*, people who are living here for a longer period of time, and who get to know the environment fairly well. Sometimes, especially in connection to the most crowded tourist-seasons, there are performers who dance with fire – or “swallow” fire – for fun and entertainment at these parties. Drinking beer and smoking pot was quite normal in this setting.

Palapa Papaya also arranged *fogatas* occasionally, where workers and volunteers sang and told stories with the children, who were thrilled, and who looked forward to these occasions with great expectations. A volunteer also danced with fire, and she earned a lot of extra popularity. During the camps with children and youngsters with and without disability, and in connection to school holidays, this is a favourite activity for the young participants.

Other nights many volunteers went out to one of the cafes, bars or restaurants in the village. One, *The Dragonfly*, was especially popular with the volunteers, and also with students from the Ocean University. There people would drink coffee, beer, soda water or drinks, smoke a cigarette, and have popcorn, which they serve for free. I would often pass by my friend and informant Garp, who lived next door, if he was not at the bar already. His health was bad at the time, due to increasing pressure sores, and I knew he had a lot of pain, and therefore both I and others wanted to cheer him up.

Once in a while the volunteers would bring some of the youngsters with special needs to the disco in the night. Especially Sara, but also Chico loved that. They would be dancing in their wheelchairs with someone guiding their chairs, and someone – like a neighbour, the owner of the bar, or one of the volunteers from Palapa Papaya – would offer them a drink.

Then, when we came back late at night I would get my lap-top, and sit down outside our hut to write my daily observations. Some nights I would also prefer to stay “at home”, though, so I could concentrate on writing my field diary. Inside, my roommate Noemi would sometimes be playing her guitar and singing North American protest songs.

Chapter IV: The inherently risky search of macho respect

Anybody can be subject to violent death, dramatic accidents and subsequent injuries or impairments. Nonetheless, on the Oaxacan coast of Mexico, as in many other parts of the world, gender seems to be a most relevant variable in this respect, together with culture and class.

The body is in some sense perennially at risk. The possibility of bodily injury is ever-present, even in the most familiar of surroundings. (Giddens, 1991:126)

In this chapter I will give you an idea about how risk-seeking behaviour, as part of the local dominant macho culture (Rostas 1996 quoting Ramos 1934) leads to these results (deaths and disabilities), as side-effects, naturally. I see **risk** as a main element in the search of respect for men with and without disabilities, whether these are inherent or the result of a disease or an injury. Thus I understand risk as a cultural trait or part of the local lifestyle – or *habitus* – that may lead to disabilities. Physical risk-taking seems to be a means to obtain personal recognition, primarily among men.

I will also look for other strategies than risk-taking that young men with disabilities bring into play in their search of respect, as by becoming fathers and respectable family-men, independent business men, artisans, church leaders, or by reaching other high positions in society.

Machismo

Primarily I need to define, and discuss briefly, the term machismo; because seen as ideology and mentality it underpinned life in the communities where I carried out fieldwork in different ways. Matthew Gutmann (1996), who writes about working class men and women in a neighbourhood in Mexico City, says that “even if verbally denigrated by many, machismo is widely regarded in Mexico as constituting part of the national patrimony in much the same way as the country’s oil deposits are considered a source of national if not necessarily individual self-identity”.

Machismo connotes a set of values, beliefs and habits that are strongly associated with Latin America, especially by foreigners, and the word is increasingly used to explain various hyper-masculine ideals and practices in other regions of the world as well. Gilmore (1990) defines machismo as a masculine display complex involving culturally sanctioned demonstrations of hypermasculinity, in the sense of both erotic and physical aggressiveness.

The word machismo is used in academic discourses as well as at grass root level, both in Mexico, which is my focus, and in other countries. The term derives from the Spanish generic form *macho*, which originally refers to the male sex in a biological way. Nonetheless, when people use the terms macho and machismo today, they are usually talking about social ways of behaving as a man.

The ideal of the *macho*¹⁵, as a “real man” was brought to the New World from Spain and Portugal, during the era of the *conquistadores*. Its origin is probably, or at least partially, to be found in the Islamic cultural traditions of North Africa that heavily influenced the Iberian Peninsula until the end of the 1400’s A.D.

Historically the image of the macho, as an urban Mexican *mestizo*, was forged in the forming years of *mexicanness*, in the first decades after the Mexican revolution began in 1910, though in the beginning the word *pelado*, literally meaning without hair or peel, but metaphorically used as without education, manners, money, was used in a similar way as today’s *macho*.

The ethos of machismo in Mexico has also been linked to the golden age of Mexican cinema in the 1940s and 1950 (Monsiváis 1981, 1992).

The old films, with Cantinflas, Tin Tan, Pedro Infante and others are still shown on television. However, the current and most widely consumed variant of these characteristic films are the popular *telenovelas*, which are sent daily. Television and especially *telenovelas*; that is soap operas, are primarily watched by women. Women, who don’t have access to a television set in their home, often go to visit a *comadre*¹⁶ or familiar, in the hour of their favourite *telenovela*, so they can follow the action.

The urban stereotypes have to a large extent spread through all Mexico in the century after the Mexican revolution. They arrive through school syllabuses, in educational and institutional settings, through literature, art, and popular culture.

Lyrics in Mexican popular music are also filled with gender stereotypes, which are consumed en masse by the population, via radio sets, at home, and typically in bars, *cantinas*, where primarily men frequent. I know of little more melodramatic scenes than the drunken *señores* who gather in the local bar on Sunday to drink, talk, sing, cry and occasionally fight. Here is a typical *ranchera* lyric which exemplifies what might be recognised as a macho ideal:

¹⁵ Among the majority of Mexicans, the term *macho* has long since been used in reference to animals, and especially mules.

¹⁶ *Comadre* literally means a co-mother, and is the female version of the more known male institution of *compadrazgo*. A *comadre* can most easily be described as a very close friend or a social sister.

Ranchera lyric

No volveré

Cuando lejos me encuentre de ti
cuando quieras que esté yo contigo
no hallarás un recuerdo de mi,
ni tendrás más amores conmigo.

Yo te juro que no volveré
aunque me haga pedazos la vida
si una vez con locura te amé,
ya de mi alma estarás despedida.

No volveré
te lo juro por Dios que me mira
te lo digo llorando de rabia
no volveré.

No pararé
hasta ver que mi llanto ha formado
un arroyo de olvido anegado,
donde yo tu recuerdo ahogaré.

Fuimos nubes que el viento apartó,
fuimos piedras que siempre chocaron,
gotas de agua que el sol reseco,
borracheras que no terminamos.

En el tren de la ausencia me voy,
mi boleto no tiene regreso
lo que tengas de mí te lo doy,
pero yo te devuelvo tus besos.

No volveré...

Autores: **Esperón** y **Cortázar**¹⁷

I won't come back

When I am far away from you
when you long for me
you won't find a record of me
nor will you get any more love from me.

I promise you I won't come back
although life might tear me apart
if once I loved you like crazy,
now you will be fired by my soul.

I won't come back
I promise you by God who watches me
I tell you this (while I'm) crying of rage
I won't come back

I won't stop
until I will see that my tears have formed
a stream of oblivion inundated,
where I will drown your memory.

We were clouds which the wind parted,
we were stones that always hit,
water drops that the sun dried up,
drunkennesses which we did not end.

In the train of solitude I go,
my ticket have no return
what you have left of me I let you have,
but I give you your kisses in return.

I won't come back...

¹⁷ Helpful collaborators at the library of El Colégio de Mexico could not find when No volveré was written, but Ernesto Cortázar died in 1953, thus the song is from that year, or some earlier.

The protagonist of the song reveals himself as a bitter-proud and unchangeable man on the surface, who blames his failure on the woman who left him or betrayed him. He admits and exemplifies that he has got soft feelings, though these can not be accepted any more once his feelings and self-respect have been hurt.

In the introduction to “The Meanings of Macho”, Gutmann (1996) says that “...what it means to be a macho – whether it is considered brutish, gallant, or cowardly – changes over time for various sectors of Mexican society, and we must not ignore the often elusive and mutually exclusive ways in which this catchword is employed today”.(Gutmann, 1996:3) In a later chapter he exemplifies and says that for older men (in a neighbourhood in Mexico City), “to be a macho more often means to be *un hombre de honor*, an honourable man” (Gutmann 1996:221). Younger men, at least in the City, sometimes have another understanding of what it means to be macho, and often prefer the more neutral word *hombre*, which means man.

The term is also implied and used as a catchword in local discourses, in very different contexts. Its meanings and values do certainly also differ according to place, audience and setting. Generally though, machismo as ideology implies male superiority over women. But clearly, machismo is not reducible to an ideology of male chauvinism. As Roger Lancaster (1992:19) stresses in his study of post-war Nicaragua, “machismo is resilient because it constitutes not simply a form of ‘counsciousness’, nor ‘ideology’ in the classical understanding of the concept, but a *field of productive relations*.” (My emphasis.)

The term *machista*, which is a substantiation of the “ideological” term machismo, connotes a man who has internalised and tries to live up the machismo ideal, and today, in my experience, it seems to be a term that is used almost inclusively in negative sense, with a strong misogynistic undertow.

In the context of my fieldwork I did not experience very much use of the word macho, and less ‘machismo’. Nonetheless I felt that I did experience a “feeling”, an “air” or an “ethos” of machismo, somewhat different to what is normal in Norway.

A Mexican man, to be considered a man, should show himself to be tough, and canalise his emotions through aggression, which is perceived as proper masculine behaviour. He must show himself *macho*, for example by enduring pain or by taking different types of risks.

Aguatepec and Laguna, as well as most other small locations in Oaxaca, are communities primarily made up of poor peasants or fishermen, unemployed or underemployed persons, *jornaleros*; day workers, manual workers and service workers, and the risks men take are mainly physical.

Time and time again this was demonstrated, in small ways and in some dramatic incidents, where risk-seeking behaviour was at heart of the action.

During fieldwork, I got to know several young men who are disabled after *accidentes*. Garp, Tito, Benito, Tomas and Jimador are all paraplegics after situations where they have put themselves at high risk. Of course they did not ask for, or expect, bad luck to hit just them in the moment it did, but people in the region expect such misfortunes to happen to men to a much higher degree than to women, as risk-taking is considered a manner to prove that you are a real man.

Three of these men were injured and impaired after gunshots, one after a motorbike accident, and one after falling down from a palm tree. When I was back for a month in 2005, there were two new temporal patients with spinal injury. Martin had been shot and become a paraplegic, while 15 year old Antonio, who was stabbed in the back with a *machete*, was only partially lame. He was able to regain much of his physical ability during the period I was there, through physical therapy, personal bodily engagement and motivation to carry on.

The following two dramatic incidents happened while I was in the field and heard the stories, and I will use them as illustrations of what I see as a male cult of risk-taking.

Accident

On January 2, Timo, his sister Dulce, and I went to a little beach, *Playa Iguana*, at the edge of the village.

The weather was beautiful, as usual this time of year, and a lot of people were spending this day at the beach. Timo had told me to come early to his house, so I could meet some of his family, who were visiting for Christmas. The family have settled in the silver city of Taxco, in the mountains of the neighbouring state of Guerrero. I was told his uncle is a fun man, who grew up close to Timo's father in Comintla. During Christmas the family of four stayed with the children's grandmother in Comintla, but every New Year's Day they came out to visit cousins who have settled in Aguatepec.

On arriving Timo's house this morning, the visitors were not there yet, but they were supposed to come by in the evening. We therefore went to the beach, as planned, but we returned quite soon, as it was all too crowded.

On our way back, we climbed up the little hillside that frames Aguatepec to the east. Standing on the top with the kilometre long main beach in front of us, Dulce insists that she is seeing her mother in the middle of the crowd at the beach, because of the red colour of her dress. She is coming in our direction, but of course without seeing us. "Why on earth is she so much in a hurry?" Dulce wonders.

Coming down the hill, after crossing the dry river at the bottom, we part. I take the short-cut crossing the beach to go to Palapa, while Timo and Dulce head home. On my path I nevertheless encounter Timo's mother, who hurries in the opposite direction with Lalo, Timo's youngest brother and a young girl, about Dulce's age, who I haven't seen. From the mother's fixed gaze, almost farcically serious, I understand that something critical is happening. She tells me an accident has happened, a man, father of the girl on her side, has fallen down from a palm tree, and they don't know what will happen, if he will die or not. Someone brought him to the hospital in Comintla.

The young girl hadn't been informed about the case yet, and now she starts crying. I try to console her, saying that everything will work out fine. Now Timo and Dulce appear, wondering what is happening. Lalo gets all geared up, talking and gesturing when he tells his siblings about what has happened. Timo criticises his brother for losing his head: "Aren't you a life guard?" he asks. "Serenity and patience; it's good for nothing that you scare the girl this way."

When we reach the main road we get hold of one of the many *colectivos*¹⁸, and Lalo takes the young girl, who is one of the cousins they were expecting for dinner today, to the hospital in Comintla to see her father. The rest of us run up to Timo's house to tell the others what has happened, and actually another phenomenon has occurred: Timo's dad has unexpectedly risen from his hammock, where he passes most of the day, and hurried off to the hospital to see his cousin. When the father returns he brings the bad notice that his cousin has died, in fact he had died at once after his fall. Even though Timo's father was not there when the accident happened, he now tells us vividly about the event. Cousin Julio and his family had not passed by Timo's family in the morning, as planned, but went up to *Arollo Tres* – another part of the village, to see other relatives. Cousin Julio started drinking, before he decided to go get some coconuts. In his youth he used to be an excellent climber, but now he was not as young and fit as he probably remembered himself to be. In fact, his wife had tried to convince him not to go up there, but he had already made up his mind and was not willing to give up the idea. Then he was quite successful and reached the top without major problems.

Uncle Julio had a special technique for gathering, or unloosening coconuts. Instead of pulling them with his hands, he just positioned himself over the nuts and kicked them down. This morning he had already kicked down a couple, when he suddenly hit a rotten one, lost his footing and fell down, hitting the ground with his back. Since then he was unconscious.

Now the whole family goes to Comintla, where they will wake over the uncle the whole night, while Timo stays at home to guard the house.

When I return to Palapa, I stop by Garp, a bit emotional, and I tell him what has happened. The story is parallel to his: only that Garp survived his accident, he just ended up injured, and I know he is struggling with much pain. Garp is sad to hear the notice, "but what can we do about it?" he concludes.

Passing the kitchen in Palapa, I relate the story over again to the cooks. Doña Mari says; "how good that he at least died at once, so he didn't have to suffer, as Garp does."

The next day I visit Timo's house early in the morning. The mourners are also coming back now, and only the father and Lalo are staying in Comintla, to dig the hole for the coffin. The women return to Comintla after picking out what to wear for the funeral. The two daughters put on jeans and the mother a skirt, as always. They also bring clothes for the two men who are working. Timo is more preoccupied by whether his father has got something to smoke. He finds a bit of *mota*, which he gives to his mother, just in case.

A bit later I go with Timo to Comintla, where we run into the Procession with the coffin in the street. Right behind there comes another group of people with a coffin, and everybody join together walking to the church. Moments later there comes a new crowd, with a third corpse, and it starts getting chaotic because of all the people. Reaching the church it is overcrowded, and we go to sit down in the shade outside the building, together with a lot of people.

The following day I procure being the first to arrive for an extra-ordinal meeting in the group of volunteers. I've been told that Tomas, our coordinator, is angry with me because I didn't show up for the regular meeting yesterday, and in fact only two volunteers had been there. I tell Tomas I couldn't be there yesterday because of the funeral, and it's alright, before I go to search for fellow volunteers. When I hook up with the young doctor Esteban, who is doing practice here, I tell him about the incident with Timo's uncle. "Shit, how bad" he says; "but *menos mal* (better) that he died then, so he didn't end up as Garp."

¹⁸ A taxi that drives to a fixed destination whenever the car is full

A couple of weeks later, Timo lost another uncle, in an even more dramatic way:

Murder

They said that uncle Bowel actually received the death that he was looking for. Timo's dad says he had told his cousin to be careful and not look for trouble, but Bowel just didn't care.

They didn't understand why he cared to look for Cassandra. She was a married woman, and moreover Bowel had his own wife, who they considered to be much better. Though his wife did not live in Aguatepec, but chose to stay in the capital.

Uncle Bowel was a taxi driver, and these days things went real smooth for him, because he was a good friend of the new district major (*Presidente*) in Comintla, and therefore worked partly as his chauffeur.

When Bowel went to look for Cassandra, he used to give her some money for her husband, so that he could go and buy himself some *mezcal*. Then the husband, who was a drunkard, didn't get home until the next morning, or late at night, because he stayed drunk in the streets.

The night of the murder the husband came home unusually early; he must undoubtedly have known what was going on. He found the two lovers in bed, and stabbed uncle Bowel to death, almost cutting his head off with a *machete*. He also, supposedly, tried to kill his wife, who nonetheless was able to escape. She hid inside the territory of Palapa Papaya, Timo says, at Embla's place, together with her daughters. Embla is the centre's driver, and she drove Cassandra and her children away so that they could escape further early next morning. They also went to warn her oldest daughter, who was married in the village of Aguatepec, and the next day they all escaped together. The escape was primarily motivated by fear for the husband-father-murderer wanting to kill his unfaithful wife, or that uncle Bowel's sons would come to Aguatepec to seek vengeance for their father's death.

As a background for discussing these two incidents, I will now look at current statistics on social violence in Mexico, through official records of violent death. The notion of violent death includes deaths due to murder, suicide and accidents.

Violent death counted up to almost 70 % of all deaths for men between the age of 15 and 25 in Mexico in 2001 and 2002, according to official statistics from the INEGI. For the overall population the percentage of violent death was 11.5 % in the same period. Between 1990 and 2005 violent death was quite constant in relation to other causes of death, with a variation of less than 2 %. The "extremes" were the years 1997 and 1998 with 10.5 % and 12.4 % respectively. For men between 15 and 25 years, the variation was almost 10 % in those two years (61.5 % vs. 70.5%).

For women 2001 represented a peak, when 40.3 % of women between 15 and 19 years of age suffered violent deaths, contrasted with 27.5 % in 1990. Roughly 5 % of all women suffered a violent death in the years between 1990 and 2005, compared to more than 15 % of all men in the same period.

Accidents account for the majority of violent deaths with roughly 67 % yearly between 1990 and 2005.

A higher proportion of female victims of violent death (77 %) die as a result of accident than the percentage of men who suffer this type of violent death. For all the population between 5 and 49 years, the death rates caused to violent deaths are higher than average.

One reason for these figures is that fewer persons in younger age groups suffer a “natural death”, and because people in these age groups to a higher degree expose themselves to risks related to play, work, and traffic. Personal and social disagreements, which can lead to violence, are also important factors which contribute to a high number of violent deaths.

Death is not the sole outcome of an accident or an attempt at homicide or suicide. In many cases the victim will survive, many with injuries and impairments as result.

The category of “accident” clearly hides much violence. This is a fact that the INEGI are aware of, and which they partly explain with “a culture of no-report”, a cultural tendency of not reporting violent crimes to the police. My friend and informant Alexandra said she was disappointed that her husband Benito had not reported the attack he had been victim to. Benito had been disputing a terrain with a former friend, who became an enemy due to this quarrel. His aggressor had failed to kill him, but he had caused him spinal injury which resulted in paralyses from the waist and down. He had almost died, from lack of proper care in the isolated mountain *ranchería* where the family of eight lived before they got in touch with Palapa Papaya. Although Alexandra was disappointed by her husband’s lack of action, she grounded this in the fact that Benito has few brothers who could defend him in the case of conflict.

According to the Pan American Health Organization¹⁹, accidents were the main course of death in the population group between 15-24 years old in 1999, with a rate of 31 out of 100.000 inhabitants. For the same year it was estimated that men between 15 and 19 years of age are 2,5 times more likely to commit suicide than women, 3,8 times more likely to die as a result of accident, and 6,5 times more likely to be a victim of homicide.

So, despite limitations in the social violence statistics, it is possible to conclude that violent crime in Mexico has got a masculine face. Men are the ones who most often incur in reported crime, men are the ones who most often suffer fatal accidents, and they are also the most frequent victims of homicide.

On this background my thoughts on the deaths of the two uncles previously mentioned are not very surprising: It seems that their incorporated culture drives them to take risks, to prove themselves as men. It is a search for recognition and respect. Recognition is a basic socio-cultural human need, which takes different forms according to age, gender, personality, culture and context. The lived culture of males in this setting places a high value on risk, and the fact that men might hear warnings against their way of

¹⁹ PAHO, regional office of the World Health Organization, WHO.

action, or doubts about their ability to go on, might utterly motivate them to act. I suspect they want to show off and impress, in a very straightforward way, but this is probably not a reflected or even conscious wish. This is *habitus*, following Pierre_Bourdieu (1977), their incorporated culture; this is what feels right and normal for them to do.

Marit Melhuus (1996) points out that men are classified along a continuum, in positions relative to each other, as either more or less a man, whereas women appear to be classified discretely, as either decent or not decent. Therefore masculinity can be, and is, continually tested.

The two accidents are examples of male risk-taking which commonly takes place in these surroundings. Usually such actions do not lead to tragic accidents or deaths, but unfortunate results do happen repeatedly, and under other socio-cultural surroundings these risks would have been managed differently.

Uncle Julio was reportedly an expert coconut-climber in his youth, and that embodied memory was apparently what he gave importance to. On the day of his accident he was celebrating a new year with his family, while drinking beer, and perhaps he wanted to show them his strength and ability, and above all his independence, because he did not care about the warnings he got from his pregnant wife. He neither considered the stories he previously must have heard of accidents in regards to such climbing, nor his current physical condition.

Uncle Bowel plausibly was aware of the risks he took by engaging himself with a married woman. His cousin Pancho also told him explicitly to be careful. Afterwards his friends and family said that he actually “received the death he was looking for”, in other words that he knew perfectly well the danger he exposed himself to, and that getting killed was a natural result of his behaviour. He got what he deserved.

At his mourning people were crying, and said that they missed him, but they also cried because he had been acting like a fool, they said. Women from Palapa Papaya were sad because he had died, because he was one of the few taxi drivers who used to help them when they were travelling with disabled children, and sometimes he also gave them a ride in his car for free. I guess he also might have tried to propose intimate relations with some of them, and possibly this was the way his relationship with Cassandra started.

Thus, Uncle Bowel enacted a *macho script*, probably not because he consciously wanted to embody a macho ideal, but because the behavioural pattern was there for him, and he knew how to use it for his own purposes, or in accordance with his own feelings.

The betrayed husband also acted out a *macho script*. He was supposed to take revenge and restore his honour as a man, to himself and to others. In fact he had already announced a new death to come at the initiation of the new village cemetery, only days before he killed Uncle Bowel. Another drunkard and

*compadre*²⁰ of the betrayed husband had been the first to be buried in the village cemetery. On that occasion the future murderer was sending up fireworks, which is customary at burials in Mexico, in order to celebrate and mock death. Outside the cemetery *el cohetes*, the firecracker, which was the name the murderer was commonly known under because of his habit of sending up explosives, foretold that his currently buried friend should not stay alone for long. Someone else would soon accompany him, he told Pancho, Timo's father.

Men seeking respect – strategies

Accepting and respecting one self is decisive for each one of us in order to build our identity as persons, but self-respect is interconnected with social and personal recognition from surrounding people. Identity construction is now seen as a multidimensional process which takes time, and which people both with and without disabilities use various amounts of time and energy on carrying out.

If we take my understanding of the local masculine ideal as a premise, there still exist alternative non-violent strategies for men, with and without disabilities to seek respect without losing their macho dignity.

Sports

Participation in sports is one of these strategies that my disabled friends and informants apply successfully in order to relax themselves and have fun. The competition aspect is also important, both in formal competitions and in play.

Prior to my arrival in the village several teenagers and young adults had used to meet more or less regularly to play basketball on wheels, but while I undertook fieldwork their exercise habit was on decay, which seemed to be linked to their "star-player's" inability to play.

I was told that Garp was the most talented player, but I was not able to see him in action, because his health kept worsening, and he had to stop practising.

However, throughout fieldwork Garp kept on talking about playing basketball, but everybody knew it was bad for his bodily health, although it was probably very good for his self-esteem. Due to these conflicting consequences I never asked him to go playing either, and it seemed like the whole basketball-thing was ceasing. There was always some reason for not playing. Someone had left the ball at home, or they were not enough players to form teams.

²⁰ Here understood as friend and drinking companion.

Life-saving

Another strategy to get respect as a man is by joining the voluntary life-guard troop. Timo has been the most active in this respect. As mentioned he is a guy in his early twenties who has got polio sequels, and therefore need crutches and leg braces to be able to walk. For long distances, and for playing sports, he does prefer his 'mobile', that is his wheelchair. In the water, though, he does not need any special equipment, but he enjoys riding a body board and a flipper.

The village beach, which is a popular travel destination for backpackers, is broad and open, with the Pacific Ocean roaring off shore.

Since pre-historic times and up until current days, a lot of people have drowned on these beaches of the Oaxacan Pacific Coast. Drowning can probably never end completely, due to the dangerous geographic features of the coastline, but in the last decade lifeguard groups have been formed in most coastal villages. This is without doubt the main reason why deaths by drowning in Aguatepec have been reduced substantially since the first lifeguard group was formed in 1995.

Here an old American surfer started to train local youngsters, on request from a volunteer at Palapa Papaya. The rehabilitation centre was thus closely involved with the life guard group right from the start, and they still train both the voluntary life guards and their own employees and volunteer workers in the CPR (Cardio Pulmonary Resuscitation) technique.

Timo was accustomed to the ocean from he was very little, when his father used to carry him down to the beach every Sunday to bury him in sand, standing, in order to strengthen his legs. This procedure was also approved of by the American natural doctor Palmer Brown, who had settled in the area and gave alternative medical services for free, and who would later found the joint school and orphanage Palapa Papaya. After staying in the intense heat of the sun for as much time as he could bear, Timo's dad threw his little boy into the ocean, and he enjoyed it, and later he learned how to manage the waves and the undertows.

With his previous experiences in the ocean, and with new-won knowledge from the lifeguard trainer, Timo was able to integrate in the group on a par with non-disabled youngsters. Being part of the lifeguard group, and saving people's lives in the ocean, is meaningful personally and socially for the integrants of the group. They gain respect both from their fellows, from strangers, tourists, and from local people who work or live at the beach. People will talk about their merits both in the village, inside the group, and even internationally. Getting this sort of respect from others helps strengthening one's self-respect. Several men with disabilities have received training with the lifeguard group, something they talk about with pride.

Garp: I am a man and I will keep on being a man all my life!

My first impression was that there was something wild and impatient about this man, who moved about in his wheelchair. Where his legs should have been there was nothing. His eyes were hungry, and it seemed as he was willing to do whatever fancied him. He was joking and laughing, sometimes singing and playing with kids at the centre, and he was flirting with most of the women at the rehabilitation centre; embodied habits that seemed to have been there always.

He was in the beginning of his thirties. He seemed to be the guy that you must love or hate.

Garp got his impairment at the brink of adulthood. Doctors had to cut off his legs, one by one, in the following two years after his accident, due to gangrene. In a conversation he expressed that he was actually glad to get rid of those legs, because they didn't serve him anymore. I understood that reaction, and compared trivially to how I had felt after my accident. I got serious injuries, and the fact that a root of one of my canine teeth had also died, making the tooth slowly darker and looser, was clearly a bagatelle, but my reaction to my dentist wanting to save the case, was parallel to Garp's; "just get rid of it, it doesn't serve me anymore". Nevertheless; in retrospective I am glad that my dentist convinced me to save the crust.

In order to save ones legs after turning paraplegic, a lot more is required. A painstaking personal hygiene is essential, something that does not come naturally for everybody, especially not for men in these region, since the required practises does not fit easily into the hegemonic macho ideal of how to behave as *un hombre de verdad*; a real man.

When you sit in a wheelchair, not feeling your legs, you have to pay special attention to hygiene, and try to heal superficial skin injuries right from the start, before they develop to *llagas*; sores. These tend to pop up on your back from the wheelchair and the skin etching constantly. Some months prior to my second fieldwork, about 15 years after his accident, Garp had to have his intestines externalised. People had told me that he was just skin and bone, and before returning I feared that I would not be able to see him again.

Medically he was a renounced case, but he kept on surprising both medical professionals and ordinary people with his ability to cling to life, and during my second fieldwork he looked unexpectedly healthy. Now he had also slowed down his formerly inexhaustible behaviour.

My first interview with Garp, a couple of weeks after my arrival for my first fieldwork, was intriguing, but due to technical failure, it was not recorded. We tried to repeat the session later in the same month, and I

went right to the point of what had caught my interest, which is what he recounts in the following paragraphs, namely his most striking memories from his childhood, and youth.

Garp: Well, I remember there in the Village, my brothers and I; we were always playing basketball with our cousins. For me it was always sports that mattered the most; a little bit of football (soccer), but most of all basketball.

When I was 17 I came from the state capital in the valley of Oaxaca to visit my mother who had then settled here in the coastal region, and I liked it so much here that I chose to stay. After a while I moved to Nisatulco, to do construction work and I also entered a cool basketball team there.

In the lapse between my two fieldwork periods, Garp had turned some friends into enemies, and he was no longer favoured at Palapa Papaya, even though he ultimately had started to live quite responsibly.

He had earlier been forced to move outside of Papaya, as a consequence of not following the rules of the centre, in particular when it came to the use of drugs. Palapa Papaya nevertheless provided him with a small piece of land, right next to the centre, so that he could easily go there to work and eat.

Nonetheless, equipment from the workshop where Garp and others fabricated toys disappeared, and there was little doubt that Garp, who had lived most of his life on the wrong side of the law, was the one to blame for these incidents.

The main reason why he was now despised by many of the centre's *ordinadores*; leaders, was perhaps what he had carried out after that, which in part of the establishment's view has made him into an enemy of the rehabilitation centre. He had been promising and selling his piece of land both to Palapa Papaya, and to a man from out of town. Both customer parties paid him, and they got signed contracts, and both had also agreed to let Garp live there until he died, which would apparently not take long.

It was hardly a secret that Garp had a criminal reputation. In fact he had been imprisoned for manslaughter prior to his accident.

Confessions

Garp and I did nevertheless develop a friendship, where we came with respective confessions, and on several occasions we discussed our accidents. The fact that I had also been through a serious accident, with lots of rehabilitation training and adjustments after that, now served as a valuable experience in order to understand and identify with people with disabilities, and also to gain credit amongst them.

For Garp his accident helped him to categorise things in his life. Whether personal relations as friendships were established prior to this point, or after, were experienced as significant. Did people know the original and "real" Garp, or did they only know this other person that he had become after the

accident? I understood perfectly and intuitively how he felt, because I also had a similar feeling of a before-and-after dichotomy.

Los accidentes en los accidentes

This was a theme Garp and I discussed more than once. In Spanish, as in English, the word accident is also used as an allusion for chance. After my accident, chance, or *circumstantialities* had provided that I was found by two student nurses, who had come in a car immediately after mine. Later a doctor on her way to work had stopped and helped them. These, who were professionals, knew exactly what to do in the situation, and an ambulance and helicopter was called upon to the place of the accident. I was said to have had luck in my accident, and I later understood I should be glad and thankful, even though I also felt frightened, sad and angry.

Garp had fallen down from a palm tree, where he had climbed up in order to get himself and his friends something to drink. His friends were thus present in the moment of his accident. They did not know how to treat him in the situation, and they reacted intuitively. They were also looking for a doctor, but telephoning one was not an option, as there was no phone line.

Instead they carried him to a doctor, and they did not realise that their intended support would harm him more than help.

It was also in one of the first interviews I had with Garp that he told me he had been in prison.

Garp: ...but there is something I have got to tell you, Margarita, I haven't told you before, because I don't want you to think badly about me, but they caught me, you know, the cops. It wasn't true, but I spent five years in prison. I was accused of manslaughter and sentenced to 18 years in prison, but after five years the police discovered that I wasn't guilty, and they set me free.

Yes, after five years they let me out, man, and I felt that at last I could go on living. And I wanted to recuperate the years that they had stolen from me. I felt that I had lost my best years, but what the hell; you have to keep on living.

Why was Garp telling me all this? Why didn't he try to withdraw this information, which put him in a rather doubtful position?

One might think that Garp was so depressed and disillusioned that he just did not bother to play the theatre of social adaptation, where he, according to Erving Goffman (1963), should have controlled the information he let out about himself, in order to gain acceptance by the hegemonic 'normals', and not hurt anybody's feelings. This did not seem to be the case.

Garp was a restless guy, whose way of being, *habitus*, was breaking laws and conventions.

Stigma

In his work on stigma (1963) Goffman draws a distinction between what he calls *the discredited* and *the discreditable*. The first category stands for those persons who lack credibility, and as a result they are discriminated, or stigmatised by others, who do not (openly) belong to that category. The discredited are people who carry visible stigmas, or whose stigmatising past, for example as an ex-prisoner or as HIV-positive, is commonly known.

Persons in the other category, the discreditable, do, just as the discredited, lack a reason for credibility, but their stigma is invisible, or not known about by others. To preserve their acceptance among 'the normals', the discreditable need to maintain a strong control over the information they let out about themselves.

This seemed to be exactly what Garp did not do. What is the case, though, is that Garp can not be seen as a 'normal', because his disability is highly visible, and this places him in another category a priori, as 'deviant'. Despite of this, he could have chosen to play the role as 'disabled' in such a way that he would have been recognised as a respectable person.

Subsequent to Garp's case, I will give some accounts of men who have gained general acceptance and respect, despite of their disabilities.

Garp, however, is by most people recognised as, in Goffman's language, a *militant*, that is a stigmatised person who constantly challenges society's behavioural scripts; unwritten rules of conduct.

I was surprised when Garp told me about his rather dark past, and I felt like I had really won access to a secret back stage (Goffman 1959:112). In retrospective, though, I realise that this information would almost certainly have reached my ears in next to no time, because most people in Aguatepec knows something about Garp and have an opinion about him. Aguatepec is a small place, and although a lot of backpackers visit the place periodically, so it can be seen as a globalised locality, it is certainly also a moral community where the permanent inhabitants do keep record of each other. I would probably have asked Garp about gossip that I heard about him, or just tried to find out more about the case. Then when he willingly, though apparently a little bit reluctantly, told me about his manslaughter sentence, he made the balloon explode at once. I was taken aback, and later there was not much left to assume. In addition he also got the chance to claim that the judgment was really not true. So, perhaps he preferred to tell me about this openly, rather than having others gossiping about it. Perhaps Garp's apparent sincerity and lack of information control in reality is just the opposite?

Now he could tell his own version, and maintain that he was actually innocent.

The prison past is also able to provide Garp with a macho identity, as a dangerous man, and not just a disabled.

Garp: Then the accident happened just after I got out of prison, some months later.

Margarita: How did it happen?

Garp: I was together with some friends, and we were thirsty, so we wanted to drink some coconut juice. The other ones picked up some *cocos secos*²¹, but I said that we should better have some fresh ones, from the tree.

The tree from where I fell was only ten metres high. Earlier I had climbed trees that were up to 30 metres, easily; therefore it's funny that I should injure myself from that one.

Some days after Garp's account, I got my assistant Timo's version of the same event, as he had been there when it happened. He confirmed that they were all really thirsty, which is not strange in the hot climate of the coast, and more so because they had been working, at least the grown-ups. He says that Garp was in excellent physical shape when he came out of prison, but that this was not in order to do sports or anything like that, but rather to get away from things, so he could do burglaries and things. "You know, he was a rapist, a murderer, and a criminal from top to toe."

At the time Timo's uncle had been pretty hooked up on cocaine, and the bad life, and he was a close acquaintance of Garp.

Timo: One day my uncle had brought Garp with him to help him fence in a small piece of land that he owned up in the hills above the village. I was only a lad then, but they let me come with them.

We brought some soda drinks, but not enough. It was really hot, and I guess that I probably drank most of the refreshment we brought, while the grown-ups were working. Then my uncle suggested we should drink the juice of some dry coconuts that lay on the ground, but Garp insisted to have some fresh ones.

I remember I was a bit scared when Garp was gonna climb up, and I asked him whether he could really do it. Garp assured that he could, and anyone could see that he was very fit physically.

Garp scaled up easily, but when he was at the top he started shaking. He shouted down that he couldn't handle it anymore, but we were not able to do anything, more than telling him to try to hold on.

After a little while Garp tried to slide down on the stem of the tree, but when it started to hurt badly, he had to detach his hands and legs. He threw himself backwards, and when he fell down he hit a branch from another tree that bent horizontally against the coco stem.

That was the problem, because in fact the ground there was pretty soft.

I don't believe that Garp would have become so seriously injured, if he had hit the ground. In the situation, his back bent the wrong way, before he fell further down to the ground. Garp cried in pain, and my uncle got scared and ran away.

Thus I was left alone with Garp, and I tried to console him, but I was terrified. Then soon my uncle was back again, fortunately, together with another couple of guys. They carried Garp down to the village. There they went to see doctor Flavio at Palapa Papaya, who came with them to look at Garp.

Flavio started to prick Garp in his legs with a needle, and he was asking him if he could feel anything. Garp didn't feel anything until the doctor reached his waist. Now the doctor drove him to the hospital in Comintla, where it was officially stated that he had become a paraplegic.

²¹ *Cocos secos*, literally dry coco nuts, are ripe nuts which have fallen down from the tree, and often have some juice left.

When Garp got out of the hospital, Timo started to visit him, and they developed an enduring friendship. Possibly this happened, at least partly, because they now fell into the same category as “disabled”, and probably also because they had the crucial experience of Garp’s accident in common. Timo was growing into a youngster, and the age difference started to be less significant. Both of them were also much used to substance abuse from their families.

I believe that more important than smoking in common, was the discourse and the constant joking among the two friends. I think their friendship lifted them up together, just as it in some other ways dragged them down.

Palapa – Pueblo, or centre – village

In the village it is commonly approved that one goes to Palapa Papaya to get medical services, but many people from the village consider it wrong that the centre now help whole families of a disabled, or in other ways disadvantaged person. Single mothers, who work and sometimes live inside the centre’s area, are seen as transgressors by some village people.

For Timo, who comes from Aguatepec and has extended family here, it seemed important to distance himself from the centre, where he had spent much of his childhood. He seemed thus to be drawn between the centre and the village, constantly aware of the small variances between the two entities. It almost appeared as if the *cognitive orientation* that George Foster called “the Image of Limited Goods”, which has at its base the nature of limited land, was pervasive among peasants in the village, (Foster, 1965:297). In Palapa Papaya, on the other hand, another mentality was promoted, where they viewed work on different premises, that is; they welcomed and encouraged personal initiatives and achievements. Many of the most recent settlers in Aguatepec also employ strategies which do not seem embedded in the traditional view.

Scheper-Hughes (1992:548-549) defends Foster’s model:

Foster’s much maligned model of the “limited goods” worldview²² of Mexican peasants who acted *as if* all material and psychological “goods” were in short supply so that one man’s gain was seen as another’s loss is deficient only in its failure to analyze the social relations of production that make this worldview an accurate assessment of the social reality in which most contemporary peasants live... Limited good thinking can be seen as a healthy antidote to the industrial capitalist fantasy of “unlimited goods.”

I find that Foster in fact did explain the contextual conditions for the “image of limited goods” pretty much, and he argued that this cognitive orientation would change once the peasants experienced change

²² Foster himself explained the “Image of Limited Goods” as a *cognitive orientation*, differentiated from *worldview*, which he understood as much more conscious.

in access to opportunities (Foster, 1965:310). Still I agree with Scheper-Hughes that this kind of thinking can represent a good alternative to the “image of unlimited goods” dominant in industrial capitalist societies; when applied to material goods, but not to human relations.

Garp also had established himself in the community prior to his accident, and it seemed impossible for him to free himself from the wild image and manners he had once gained. Therefore it seemed hard for these two friends to integrate smoothly into the centre’s life.

Garp and Timo needed to be accepted as young men by the village people, and since they exist as persons outside of the centre, they can not begin to establish their identity from inside of the centre, as persons who meet the centre prior to the village can. Both have rather *militant* stances (Goffman 1963), for example in that they don’t accept alms or unwanted help from strangers. Both have removed the handles at the back of their wheelchairs, which is common among men who can roll for themselves in the area, an act which also is a statement of independency. When I asked Garp why, he explained that he didn’t like the handlebars, and that he was disturbed by people who tried to help him.

In the article “*Reconsidering the Stigma of Physical Disability*” Cahill and Eggleston point out exactly what Garp plausibly *felt* in such situations: “Every time walkers offer or grant a wheelchair user assistance, they mark their place as superordinately capable and gracious benefactors. Every time a wheelchair user accepts such assistance, they mark their place as subordinately grateful beneficiaries”. (Cahill and Eggleston, 1995:694). Such “place markers” (Clark, 1990:310, quoted in Cahill and Eggleston) are expressions of relative social rank, and I see the act of removing handlebars in order to prevent unwarranted assistance as an act of resistance.

Boys here are also preoccupied with the *appearance* of the chairs, and they are always prepared for changing their current chair for one that is more sporty and comfortable. The centre receives used wheelchairs and other sorts of equipment from donators from time to time. Also, during my second fieldwork I was told that they might receive chairs especially designed for basketball from a Swedish sponsor-group, and the boys were eager to get them and start playing, something which has now been realised.

Pride 1:

During fieldwork I experienced several situations where friends and informants reacted in a proud way when they were subject to what they felt as insults. One such incident was an invitation for an ice-cream: My fellow volunteer Barbara and I were taking the young internal patients Sara and Chico for a walk in the

village. There we met a friendly young tourist, who I had been talking to previously. He invited Sara and Chico for an ice-cream each, an indulgence they welcomed with smiles and laughter. Then we saw Garp and started talking, and the tourist asked him if he would also like an ice-cream? Garp refused and wheeled off hurriedly.

In a way I understood him, even though he seemed to overreact. He is a grown-up man, who looks like a man, talks like a man, and even “wheels like a man”, and it showed that he did not feel good when he was treated in the same way as children. He felt the gesture as a marker of difference, and he refused to take the correspondent subordinate position.

Also, the simple fact that he is able to talk makes him different from the other two persons. Chico and Sara are very communicative facially, but they are nonetheless not able to talk. They have got Cerebral Palsy, which is linked to the head, while Garp’s paraplegia is due to a spinal injury, and he possibly feels that their conditions are qualitatively different.

That episode also mirrors an occasion where Timo felt insulted: A young, more-or-less wealthy North-American tourist wanted to give him money, just out of the blue. Timo was sitting in a hammock in his sister’s outlet, and the guy, who rented there, saw him and tried to hand him some money. Timo reacted angrily, and told the guy that he could manage on his own, and he did not want any leftovers or pities.

Later we discussed the incident, and he explained to me that he gets really pissed when someone treats him that way; assuming that because he has got a visible disability, he can not depend on himself. He expressed that he doubtlessly prefers to stay poor, rather than accept mercies from strangers.

Pride 2:

Life guarding at the beach was quite another issue. Timo was part of the local voluntary life guard group, whose engagement had made death accidents on this dangerous beach drop substantially. When Timo had rescued someone on the beach he had happily accepted money, if they had wanted to give him anything, but he insisted that their joy and contentment was his biggest reward. Other lifeguards had forced their rescued victims to pay them, Timo and others told me, and I have no reason to doubt that, due to the fact that corruption is very widespread in this society. I have heard many stories of corruption in the lifeguard troop, for example from their former trainer and founder of the group, who was not welcome in the group any more, because he had been criticising internal economic practices.

What made Timo accept one sort of money contribution and not the other had much to do about respect and self-respect.

It was certainly highly esteemed not to accept money for a rescue done at the beach, but it was understood that people who had been rescued might want to make a contribution. More vital was probably the lifeguards' relative poverty and lack of permanent employment.

When I arrived for my second fieldwork, life guarding had become part of the official tourist policy. One of the former voluntary life guards, who had tried to fight corruption within the group, had now become elected leader for the whole community, and life guarding had become a respected and paid job. Though not without distress, especially within the life guard group, where they had to choose which one of them were to occupy these rare and admired positions.

Ambition:

Locally the word ambition seemed to be understood as a hostile and egotistic approach, and I believe that the two friends were not able to channel their activity through Palapa's accepted passageways, because they regarded them as ambitious. Instead they chose the "hard way", from the outside. Timo chose to live with his family and eventually entered the Ocean University in the Village, without any help from the centre. First he did not even want to study, because he would then either have to accept the entire established network of the centre, which meant studying in the state capital or live together with other youngsters associated with the centre in a house that the centre owns, or ruin his family economically. None of the options were favoured, and he chose day drifting with related substance abuse instead. Later he managed to get funding from the Ocean University, and he started studying for a professional career, but on repeated occasions he dropped out, and substance abuse was doubtlessly a key to the problem.

Garp, on the other hand worked at the centre's artisan carpentry during my first fieldwork, and all his earnings seemed to be spent on drugs, even though he claimed that he wanted to save money for an operation.

During my second fieldwork Garp worked in the private artisan carpentry of his old boss, who has now managed to go independent, though he definitely established himself from inside the centre.

In the meantime Garp has been closer to death than ever before, due to stomach complications that at some time made it impossible for him to eat and digest, and this was plausibly a pushing factor which made him change both his attitudes to life and his practises substantially. He is now living somewhat ascetically, without legal or illegal drugs, and he is devoted to God and religious practise.

During my first fieldwork I suspected Garp to be influenced by missionaries, due to his fragmented talk about God, Jesus, and the Holy Book. I also heard through the grapevine that he had been experimenting with satanic rituals. After I left I nonetheless got to know that Tito, Garps boss and close

acquaintance, was becoming a dominant figure in Aguatepec's alternative Religious Community, the Protestants, and I understood that Garp probably had been influenced by Tito's religious views.

During my second fieldwork I wanted to discuss religion's part of his life with Garp. Now, this seemed to be clearly defined, though I know things might change in the future.

Garp: I was close to wind up lately, but thank God I am still here. You know; when I was really bad, people said that I would not resist anymore, but when they see me now they say I even look chubby.

Margarita: Yes, you are always recuperating, I don't understand from where you get your forces?

Garp: I don't know where the energy comes from... I have been very close to saying goodbye, several times, but I am glad that I haven't yet! When I say to myself that it is not time yet, then it is not! Perhaps it is *la Energia*, or perhaps it is because one has got more left, and because of one-self, you know.

Garp seems to be constantly struggling, and he is attributing the fact that he is still alive to God, to Energy, which is similar to "God", only without religious doctrines, and to himself. He is certainly right. His own will to overcome his problems and to recuperate himself from bad health is essential. What is also essential and which he disregards to mention is his social capital, his relationships to human beings and institutions. The fact that Garp's life has been saved numerous times by doctors and health personnel can seem strange of him not to point out, but I believe that he sees these persons' rescuing actions as depending of his own luck or destiny. They are plausibly part of God's will or *la Energia*.

Margarita: How will you describe yourself as a person?

Garp: Well, I love to be sharing something with someone.

But to be true, when I got this disability... I thought that I was nothing anymore. I said to myself: How can I possibly be the same, when my own body had changed? Won't my way of thinking and everything change? And I remembered the time when I was walking around, and I would just feel like a small boy left in a corner.

But other times I would say to myself; no! Life goes on. And I found out that I really was the same person, and that after all I was my own person.

It is surprising that Garp describes himself as "someone who loves to be sharing something with someone". This is quite the opposite of how he has been, and still is, seen; for example by the official Palapa Papaya.

I thus choose to understand his brief "self-description" as an emphasising of the change he has gone through recently by entering the protestant group in the community, and by managing to end his use of illegal drugs.

He describes becoming disabled as ruining his self-image. His being was concentrated in his bodily abilities, and only by keeping on pushing these to the limit he seems to have been able to restore his image.

Margarita: How are your family relations, and how have they been?

Garp: Well, they are good, or aren't they?

Well the sad thing is that... we did not have much to share... and everything.

To be united, to be together always, that would perhaps have been more relaxing, for each one of us. That helps you a lot, you know.

I have always been alone in my house.

Margarita: But now you are living with your brothers, aren't you?

Garp: With Ivo and with Carlos, yes that's right. But... they are just there. It looks like we are not even familiar... We are talking very little. Why? Because there have been too many years, I think. A couple of days is nothing, but when it makes up a decade, after the accident, that is something. It is just like everything pays you back, you know. Just as enough is enough... we do have something, but it is like we don't find a way to be sharing or talking with each other. And they have got their own manners and everything...

Margarita: What about your nephew Jaime, who used to work at Palapa Papaya in his school holidays? Now he has got a scholarship to study medicine from the centre, hasn't he?

Garp: I don't see him much.

Margarita: But he is nice, isn't he?

Garp: Aha, you know to be true I did only really relate to him here, in Palapa. The few times I went to my sister's house to ask for her son, he was never there. And now he is studying out of town. No, I am always staying at home, these days. Sometimes I go out on the road in front of my house, and then I go back, that is what I am doing. There is very little sharing with my family or things like that. Nothing, actually.

It is a bit sad because for me it is a life, and I live it like this (*he holds his arm vertically, to show that it is monotonous*).

Well, to be true it was always like this. I was always alone in my own world; they separated from me when I was around 12-13 years old. Then I was left alone.

Well I lived more with my aunt and uncle, that's why... and with my cousins. But they are not around here; they are at home, in Casablanca (the mountain village where he comes from himself). With them I am on good terms, because we lived together, a long time ago. Chatting, joking, things like that.

With the children of my mum and dad... we lived separated, always.

Not surprisingly, Garp comes from a "broken home". Family has nonetheless been his most stable resource, although his family has never provided him with the kind of support and unity that he in retrospect would have wished for. The only one in his family who has been able to raise herself out of cruel poverty is his sister, who has married and lives a somewhat stable life in the village of Aguatepec. She is not on particularly good terms with any of her brothers, who all have criminal carriers. Nevertheless; her eldest son Jaime had the opportunity to work in Palapa Papaya in his school holidays,

and currently he receives a grant from the centre to study medicine in the city of Oaxaca. I have observed that Garp and his nephew seem to get along well inside the centre, talking, joking, and having meals together. Garp does however complain that this relationship was only played out inside the centre, which thus seems to have represented a protected space where the uncle and nephew could relax from the wider community's moralising eyes. There they could let family roles have priority over the moral dichotomy of normal (good) – deviant (evil) which they would else be caught up in.

Garp: The most important thing about all this, you know, is that the fibre within oneself has to be positive...

Someone who can accept life, and accept how one self is, that is life. Then it doesn't matter if there will come a strike, or a ton of weight. You can manage, and avoid things. And it doesn't matter what others think, and it doesn't matter what they keep on thinking; whatever people think about me, it doesn't matter!

Margarita: Then you have got very strong forces!

Garp: Very strong, even with the diseases I say no; if I have managed so far, ouah; fight against death and life! And I keep on feeling the best that I can, and I will jump if I can!

It is plausible that Garp has gained some of his optimistic statements about life from the congregation where he is now part, and in that way religion has become his new "opium" (Marx 1844). What is also certain is that Garp has got a "player's spirit". He enjoys not only playing sport, but also the game of life.

Margarita: How has disability influenced your life?

Garp: A lot, because with a disability one can find many things that are better and worse. It gives you an example of how life is.

Margarita: Yes, certainly; you may even get stronger than before, I think.

Garp: And now I accept it; that is what I didn't do before. I miss my physics, as when I was a normal youngster....

Garp highlights the learning aspect of disability, an aspect persons both at the rehabilitation centre and in the congregation are well aware of and help spread. The crude fact of attaining a disability might itself stimulate (self) reflection and consequently learning, but a person is likely to pass stages of anger, disbelief or depression before eventually reaching self-acceptance, what Garp's story exemplifies.

For Garp the bodily change he experienced as consequence of his accident, with the loss of physical function, was traumatic and unacceptable. His recognition as a person, and his self image, had been dependent on his physical abilities, for example his participation and achievements in sports. Participating in basketball and racing on wheels later seem to have helped him restore some recognition and self-acceptance.

Garp: We are not yet brothers and sisters all of us. I love the idea, but it is just an idea. The ideals are always high, you know. I learnt a lot about that when I was fighting, against my own physics, against my physical limitedness.

I also wondered in what way I could experience myself, and develop myself once again. And be able to walk again.

Ssssh, I was travelling, you know, although in my mind. My mind did lopes around the world, but I did not find any solution...

Until I said to myself that "enough is enough, - what is the point about thinking and not finding any solution?"

I learned a lot of things in rehabilitation; to value life, for example. About our physics, and... my own limited physics. The ability to put up with oneself, even with an imperfect physics.

For example the fact that I am a man; I will keep on being a man all my life, you know.

Garp seems to have related some of his congregation's discourses to his own experiences. His fighting against his own physical limitedness has been painful, but this does however look like a very human way of reacting to such a fundamental personal change and loss. Of the six men with spinal injury whom I came to know and interview during fieldwork, only one was essentially optimistic about his future at an early point after his accident. The rest needed many months, and often years, to achieve a general acceptance of their situation, and hopes for their future. All had some relation to the centre, but the one who was less dependent on the centre was also the most optimistic. This does not imply that the centre has a bad influence on their patients' situation. Instead the optimistic Jimador was the one who seemed to have the most social, cultural and economic capital. He was also older than the rest when he suffered spinal injury.

For the rest, Palapa Papaya seems to have been their only rescue, and a place where they have learned to accept their new selves, in different degrees. Their degrees of self acceptance seem also to be interdependent on their ability to work and provide for themselves and their family.

In Laguna, in contrast, I knew only one person who had suffered spinal injury. Manuel was very well integrated into the community, where he had the valuable occupation of knitting fishing nests.

Margarita: What do you think about the future of disability?

Garp: Disability has a future. There is a lot of technology, a lot of things to try.

Margarita: Yes, and what do you think is vital for disabled people in order to live good lives in the future?

Garp: Knowing that one pays for everything in this life. Be it men or women; a lot of people think that they can not have a partner anymore. That is what mostly turns us off, and people start to shrink. But it is not true! If they want to keep on being the way they used to be, they can do it, and they can live just like anybody else.

It is hard, but life goes on; and they can live with a partner.

They can live a life... just like another. Perhaps a few people might be confused, but why are we confused? If we are living just like anybody else? With a partner on our side, talking. Yes, there is future within a disabled person, not everyone has got the same abilities or disabilities.

There are always some who have got advantages, and others who don't. Some who do not have much power, or how could I put it: Energy, one's spirit, often what really turns people down is that others say that they are not worth anything any more, "now I can't even have relations with my woman," things like that, you know.

But it is not true; they can! – There are a lot of techniques to do it.

Margarita: You are right.

Science has advanced so much now, and that is why I do not let myself down so easily, when they say "you are nothing worth any more." "No, because you are only seeing my disability, you are not watching what I am, what I can be worth!"

But I will not look for the person who prejudices me, because I do not want to feel the same way again. I try to avoid those circumstances, because the future; however you look at it; if you want to have something; just keep on, you see? Nothing else matters. With delight and joy, together with any friend, or girlfriend, in the manner that suits you, enjoy!

Garp turns optimistic when he is talking about the future possibilities of other persons with disability. He uses himself as an example, and it seems like he has adopted discourses provided by the protestant congregation and the rehabilitation centre.

Margarita: And, wait a minute; did you leave all your bad habits?

Garp: Oh, yes; thank God.

Margarita: Well, you look more awake now, even more geared up.

Garp: My vision was to beat all challenges, but earlier I just talked and gossiped. There is a saying that goes like this "a man has to win over his vicious; or the vicious will win the man", and really; often that was what was happening to me.

Until now; now they are all gone, all the bad habits that I had; drinking, smoking...

Margarita: Drugs.

Garp: Drugs also; but now I am talking honestly to you, because I made it. And I am not thinking of throwing myself any step back or even look back at all the things I did, I decided to stop, and I see that that old bag does not suit me any more!

This interview with Garp, and everything I learnt about his current situation, shows me that he has made a remarkable switch in his being. I know that this did not happen until he touched the limit between life and death, and after he had turned some friends and supporters into enemies. Now his new escape and solution is religion, though in the interview, he did not mention this especially. Perhaps he was a bit uneasy about it, because religiosity did not fit much with the impression I had of Garp from last time. Later I had the pleasure of assisting a small religious gathering in the house of Garp's friend and workmate Tito, the former manager of the toy carpentry in Palapa Papaya. I was surprised to see Garp there, but I was certainly pleased. At the meeting he assisted Tito; the two men in wheelchairs were sitting on opposite ends of the small room, and the other participants on the sides.

People from this protestant community helped Garp economically and practically when he was in hospital recently, and they keep on helping him now.

Thus Garp has shifted from depending on Palapa Papaya's support, to the church'. He is also working with small things himself, like fabricating bracelets and necklaces out of thread, and simple electric reparations. In fact, during this interview, my tape recorder started tricking, and Garp wanted to help me repair it. But he was out of equipment, he said, therefore we needed to borrow something at the centre, where we were meeting.

"It is better not to ask," he explained, "because they will not let me enter the carpentry." Therefore we explained the situation to a volunteer, who turned out being an electro domestic engineer himself. He came with us into the carpentry, where we picked out the tiniest screwdriver, which however was too large. "We have to modify it," Garp decided in a straightforward way, and he showed me where to do it on a machine. Suddenly Tomas from the centre's coordination came into the carpentry, announcing in a loud voice that "Garp is not allowed to visit the centre's workshops." "Ok, I will leave," Garp said. I tried to explain the situation, but Tomas did not find any reason to listen. As I was not chased from the place, I stayed, and began modifying the tool.

When I was finished the tool fitted, but it then turned out that the recorder needed such a complicated repair, that none of the two electric engineers would be able to do it without more specialized equipment. We finished the session, and I saw Garp sign a paper that one of the cooks handed him. I asked him what it was, and he said that he has to sign every time he comes to eat here now. That makes him try to avoid coming here, it is only when it is the last solution, he explained. I see, I said, and I remembered that he had been eating with a lot of appetite, and I understood that it had been a somewhat special occasion.

These days Garp was sorry not to participate in the triathlon competition that Palapa Papaya organised. "It hurts me not being able to participate", he told me one day that I passed by his house. He said that he would not stand the physical pain participating would spawn in his back. If he were to participate, he needed to buy some drugs, that is painkillers, and take a shot prior to the competition. The problem was that this was expensive, and he did not have that many pesos (over 200). Then, if he won the competition it would pay back, because the first prize was 1.500 pesos, an amount that however had to be divided in three equal parts, for the three team members. And then if they didn't win, the second and third prizes were less, so perhaps it wasn't even worth it, as it would probably mess up his back once again, he said sadly.

During a similar competition two years ago, Garp and Timo had formed a team, together with Bony, a non-disabled companion of Timo from the University, who ran. After the two first distances: Timo swimming and Bony running, the team had been leading, and they had strong hopes for Garp on the last distance. He had been doing his best, but on the steep road down his wheelchair had almost broken down, and he was beaten, by Felicia, a girl, who won the competition for her group.

After the competition Garp's health had worsened considerably, the sores in his back expanded, and he had a lot of pain.

It would have been likely for Timo and Garp to ally once again, and when I talked to Timo about the coming competition he expressed frustration. On one hand he wanted to stay with Garp, because of loyalty, "we are a team, you know", he told me. On the other hand Timo would not like his friend Garp to mess up his health once again, and what was more; Timo really wanted to win, in order to get the money-prize, which indeed was a major pull-factor for everyone who wanted to participate in the competition. Timo ended up allying with another friend; Abraham, who would run in the wheelchair, and his own cousin Joshua, a tall non-disabled young athlete, who would run.

I wanted to participate for fun, and in order to get a valuable participatory observation. The week prior to the competition I was exercising together with Timo's cousin Joshua, and eventually the latter's younger brother David, who is a talented sprinter. We would meet for a run at the beach in the mornings, and it was fun. We were joking, saying that the best one of us would qualify for their cousin's team, and that we should have an internal competition among us prior to the real competition in order to select the best. That never happened, but Joshua and I went to the meeting the day before the triathlon, where the teams would formally be established. A lot of men were coming to the meeting, and only a couple of women. I had formerly tried to encourage the girls at the centre to participate, and a couple of them had been exercising running. Now these two girls wanted to participate, and we found out that I could form a team with them, only that I had to do the swimming part, and they would share the running. Then we had to use a boy for wheeling, because none of the women or girls in wheelchairs wanted to participate. We found that one of the centre's neighbours, who is also a polio survivor, would do that part. Of my runners one girl had got polio sequels affecting one arm, and the other one was a pre-adolescent, with no visible disability.

Tito: Disability has made me the person I am today

Garp's former boss Tito is also a wheelchair user, after an accident more than 15 years ago. At the time of the accident, he was newly married and had a baby daughter, and the family lived in a Zapotec mountain village. The stereotype in such a situation would be that the wife and mother would stay with her family, and suffer for them. The image of the Suffering mother, exemplified in the Virgin of Guadalupe, who is seen as a mix of the Catholic Virgin Mary and the Aztec goddess Tonantzin, is the overall most important image in Mexican society. I will later have examples of women and mothers who embody this

image. Tito's example seems nonetheless to be quite the opposite of the hegemonic model, though this might also be the result of a personal development, or move, on his own part.

I do not know the specific circumstances well enough to make judgements. All I know is that Tito's wife left him and their little daughter after his accident. In an interview Tito admits that it was hard: The first year after his accident he had not been able to adapt to his new life situation, or accept his "new" self. After a year he was nevertheless given professional rehabilitation at a governmental institution²³ in the city of Oaxaca for six months. He separated from his wife because "she wanted to change her life", he says, and he chose to give her the opportunity to do so. He does not mention that his wife had then found a new man, but stresses that his daughter Dolores kept on living with him and not the mother after the separation. Dolores was also brought up by her grandmother, Tito's mother, and it is clear that her loyalty goes to her father, and not her mother whom she doesn't relate to anymore. Dolores explained that her parents had problems stemming from before the accident, and she thinks it was better they separated. When her parents married, her mother was only 14 years old, and her father was 23.

Tito's nephew Amado, who was the same age as his daughter, was born with a disability – a quite severe brain damage, probably occurring at birth. After some years Amado's parents heard about Palapa Papaya, and they were able to place him to live at the rehabilitation centre, where they visited him regularly. Through this *palanca*, Tito was also able to establish contact with the centre, and he was given practical help and funding, partly from his municipality's authorities, to set up a workshop, an artisan carpentry, in the nearest village from his *rancheria*. At a public meeting in the village held by the authorities, they found six children and youngsters with disabilities there, and all six were willing to work. The youngsters integrated a work group which was lead by Tito, where they produced wooden toys for sale.

Having a family and a steady job are both important sources for social recognition and self respect, which Tito was clever and lucky enough to attain.

Tito's "opium" throughout these years has been his religious conviction.

Tito has lived in Aguatepec since a change in authority in his village made it impossible for him to go on with his workshop there. For about ten years he was living inside Palapa Papaya, directing the same type of artisan carpentry as he had formerly been responsible for in his village. The idea was to keep on employing children and teens with disabilities, but that project was not conceivable. Here he has instead been working with young adults.

Tito: The children here are different from the children from the villages. As the children here have got the beach, and the sea, they do almost not enjoy working. They do not like to stay in one place working, but they like drifting around,

²³ CREE, Centro de Rehabilitación, subdivisión del DIF.

walking, playing. Because of that I had to change my plans, and instead I decided to work with youngsters, because the youngsters from 15 years and up do engage in the work. Yes, and they develop their creativity, they learn drawing, and they can make use of their imagination.

That's the reason I'm working with older youngsters now. Earlier we used to copy products from other workshops. We bought toys from other workshops and we copied them, but now I have decided to create my own designs. The frog, the iguana, the horse, the dog, turtles and birds. So now we make products that are more original, and also the quality: now we are managing quality. In the beginning... well, it has been a long way to go.

Tito seems to be satisfied with himself, as a father, and as a responsible worker and artisan. He is able to identify himself with his work and his achievements.

The move from his village to Aguatepec and Palapa Papaya was positive, Tito considers. Here he and his daughter could live peacefully and share experiences with a lot of people, nationals as well as foreigners. What he appreciates most is the communication between people of different ages, with and without disabilities. That is integration, he explains: "Because earlier we were very isolated, not only in the village, but anywhere." "You take a disabled person, me for example", Tito exemplifies: "just to go outside: Earlier that made me very embarrassed!" In contrast; now he has lost his fright and he enjoys his renewed self security.

Margarita: Yes; but then staying here in Palapa, we really don't have to go outside at all, because this is like a community in the community. Do you visit other places in Aguatepec?

Tito: Yes I do, I visit the artisan shops where I deliver our products, to see how the business goes.

It seems clear that Tito's respect for himself has gone through changes and development during the years after his accident. Tito has made use of external help to build up his own esteem, and his image as a respectable man. From what he tells me he seems to take something like a non-macho attitude to life, first in saying that he just let his former wife have her will and separate from him, and secondly because he has been taking care of their child.

At the same time as Tito represent a non-macho stand, I know that his brother, who is very close to him and with whom he kept regular communication despite that he had recently migrated to the USA with his wife, is quite the opposite of Tito; violent and a hard drinker. I don't know, but it is not improbable that Tito had some of the same attitudes and characteristics as his brother earlier. In any case, despite of their different attitudes to life, and the long geographical distance between them, the two brothers seem still strongly tied together, and they help each other out in different ways. Tito is keeping an eye on his brother's children, and his brother is sending them money.

In my second fieldwork period, Tito's teenage daughter and his brother's daughter, who had both been living with Tito for around five years, had migrated to California to join Tito's brother and his wife. His brother son Amado could not accompany them, and he was left with Tito, who engaged familiars from the mountains to come to live with them, and take care of his nephew. Nonetheless Amado recently died of pneumonia, 20 years old.

Doña Mari, from the kitchen at Palapa Papaya said that she thought Amado died of sadness because all his family had left him, and also because the rehabilitation centre was unwilling to take care of him any more. "You couldn't expect that his uncle Tito, who is also disabled, could take care of him properly," she said. "Well, Tito is also a very busy man", I added. "That also", Doña Mari agreed. We were meeting on *el Día de los Muertos*, the Day of the Dead, which I will relate in Chapter 6.

Margarita: Amado also lived here, I know, isn't that right?

Tito: Yes, in the other part of the house.

Now we are staying in the workshop for the interview, which is like the 'public' half of his house. The other part is Tito's private living room, where he also sleeps and cooks. "Here is his hammock," Tito shows me; "which he liked to use in the days."

Tito: First there used to be a couple of familiars looking after him, and after a year, they were caring for him here, here with Dolores. Amado lived 20 years, and for him it was a very difficult life, there were a lot of things that he couldn't do, and when he died he had started to develop more problems. He coughed a lot, and he had respiration problems.

Margarita: Just like pneumonia?

Tito: That was what it was like, but we were not able to save him.

In a way Tito is temporarily stripped of all family relations, even though he stays regularly in touch with his daughter and his brother in California through telephone. There they also find customers for him, because *over there* his products are sold.

I imagined that he also kept in touch with the rehabilitation centre Palapa Papaya, which is not very far from his new home, for example through delivering his wooden products there, but he says that he does not. He is selling his things on his own now.

Now Tito has become a central person in his religious milieu. It was not until after fieldwork that I got to know that Tito forms part of a local group of Jehovah's Witnesses. Ultimately he has become an important figure there. During fieldwork I knew other people who were engaged in the same group, which is the only established alternative to Catholicism in the village. Nonetheless, I chose not to engage in their religious life, though I observed whole families studying the Bible together, and children revising old maps of Israel and Jerusalem.

However, I saw that the break with the Catholic faith created divisions within the bigger family, because they could not agree in religious questions, and the newly converted evangelists chose the

community of the church over the family. Therefore some familiars would avoid each other during the first couple of years after a conversion, even though they lived in the same village. Despite the fact that I saw these occurrences affect some of my friends and informants in Aguatepec, and I saw similar phenomena in Laguna that created similar familiar divisions, I chose not to focus specifically on this phenomenon, more than as forming part of the background carpet. One reason was that in the field situation I hastily analysed these religious alternatives as superficial, as deliberate economic choices that the actual persons took. I thought new evangelists chose to convert primarily out of economic interests, as I saw that in this group economic accumulation seemed to be approved over spending all economic income immediately on friends and family, which was common by poor village people.

Some of the new Witnesses were ex-alcoholics or ex-drug addicts, and the group represented their salvation from that sort of abuse. Becoming part of the congregation helped them gain a strong work ethic, and I believe that it would be difficult for them to gain the same sort of support from the established Catholic elite.

During my second fieldwork I hoped to be able to look a little bit closer on religion, and be able to participate in a *culto* offered by Tito's religious community. Here I wanted to observe how they did things, and in particular to see how Tito took part.

Culto:

The *culto* takes place in Tito's house, inside his artisan carpentry, and I believe this is the first time that they celebrate a gathering here. Earlier they have rented a more centrally located house in Aguatepec, near the football field, but now they had to leave, and therefore they use the carpentry. The place suites fine; it is small, but there are also quite few people here, and the place is decently chilly in the morning, which is good, because the heat is otherwise grim.

I go there around ten in the morning, together with Carmen and Antonia who are sisters in law, and three of their children. So we are three young adult women, and three children, who come a little late to Tito's house. To my surprise I see Garp there, as I haven't yet known much about his involvement in the congregation. He sits in his wheelchair as the only one visible in the open doorway to Tito's house. The next thing which surprises me is that there are only a handful people here. I greet Garp and Tito, but we do not speak much, because soon the *culto* will start. We sit down and, at least I, wait for more people to come, but we are in effect the last ones. There are only us: three women with three children, Garp and Tito in their respective wheelchairs, and another man, who is dressed in a white shirt and who looks a little bit more serious than the rest of us.

El culto, which is the word that everybody use to describe the meeting, takes place in a room of approximately 4 square metres. Perhaps it is the word *culto* that has misguided me, because I imagined this happening to be a lot more mysterious than it will actually turn out to be. There is a lot of singing, and I believe this might be one of the reasons that Tito has gained popularity in the church. He is singing well. Everyone has got a Bible in our hands. The others bring their own Bible, and Tito lends me one of the extras that he has stored together with carpentry tools and artisan toys in the shelves on two of the walls that surround us. Antonia's twelve year old daughter Rebecca helps me continually to find the right places in the Holy Book, so I can read the verses. At one side of the room there is a long table with a white cloth

upon it, and there are chairs opposite the table, where we, the public, sit. Tito and Garp occupy the two resting sides of the room in their respective wheelchairs, so that they are opposite each other, with the table and the public on the laterals between them.

The *culto*, or ceremony, starts with Tito talking a little bit, he welcomes us and thanks us for coming, and following that he leads us through various songs. These are songs in a style of modern North American popular music: they've got rhythm, they are easy listening to, and it is difficult not to join in singing. I do, as one would expect, participate: I learn the refrains, and it is a delight singing with Tito. After several songs, perhaps half an hour, the Brother in the white shirt is called upon. He rises, goes behind the table with the white cloth, and from there he makes a speech. He talks about is the human soul. "The soul is very precious to God", he says, in fact the soul is the only thing that really matters, and he shows us several places in the Bible where this issue is treated. The preacher is reinforcing the notion that the soul is the only thing that counts for God, and not the body. In one of the songs it says that the believers will fly up to heaven like eagles, and I imagine that this must sound nice in the ears of Garp, and Tito²⁴.

Religion's force and draw on human beings is undoubtedly a complex matter, which I shall not try to explain, but I will try to show what being part of a sect means for Tito.

In some ways the group might fill the holes of relationships that his family has left, and what is more important is the fact that he counts in the group. First of all because every soul, that is every person counts, theoretically to God, and practically to the congregation.

Secondly Titos role as local leader of the congregation is a significant position socially, which he seems to embrace wholeheartedly. The fact that Tito has become a prominent person in the group seems to fill him with satisfaction and joy, and knowing that he is respected and appreciated by his flock is a source of esteem and self respect.

November 2005, a couple of weeks after I attended the *culto* in Tito's house:

Margarita: It looks like you are more involved with your religious group, now.

Tito: Well, not really. Right from the start when I came to Aguatepec, I have always liked to be in the group. Now I have been able to progress because of my faith. You never came to a church meeting previously, or what should I say?

Margarita: You're right, you know it's not until now that I see what you are experiencing, perhaps it is late, but I am very happy to know about it.

Tito: Yes, now we are making our cult here in my house. Until lately we rented a house in the centre of the village, close to the football field, and all the members in common collected for the rent. Now we got some problems with the owner of the house, because he wants to augment the rent, and we decided to celebrate our cult here in my house, temporarily. In the long run we want to build our own church, you know.

²⁴ The preacher's wording also makes me remember an occasion when a friend and I visited Garp, and he was high on something they call *cement*. He told me that he had been flying, and that he could see everything from up above, himself included.

It is obvious that religion is creating meaning in his life, and Tito has at last managed to integrate Garp into his group. Tito starts mentioning Garp:

Tito: You see Garp has been a bit in and out of the group. He has had serious problems, but he has also made errors. His land; Palapa Papaya gave it to him, with the expectation to have it back, but Garp sold it.

Now various people have got contracts on that land, but in the end; one *señor* brought a lawyer, and it seems like he is winning the right.

Margarita: I see... because now they are really angry with Garp in Palapa.

Tito: But he goes there to eat still, doesn't he?

Margarita: Sometimes, but now he has to sign a paper every time he eats, so he does not go there much.

Tito: Well; they have supported him a lot earlier, but he has not known to appreciate it. After I left the centre myself, Garp does not go there much, either.

We used to work together always, you know; Garp put together the pieces that I painted, and Palapa paid us for every piece. But well, in the latest years, you know the equipment I had in the workshop started to get lost. I said to Garp that "look, I lost equipment", and only later I realised that he was the one who took it, in order to sell it.

Margarita: But now Garp has changed, hasn't he?

Tito: Yes, but in Palapa they do not let him enter anymore, these things has happened too many times. Here I have control, you see.

Margarita: Yes, now you are really your own master.

Tito: Yes, here I can do a lot of things, but sometimes it is difficult, and I keep on thinking of the possibility of going back to Palapa Papaya, perhaps next year. And start to work there again, but the centre has changed a lot, you know, and I don't know if they will let me.

I survive here, I sell a bit. Right now I have got these pieces that I will send to my brother, by DHL, because over there it is sold, you know, in the shops. It is good to have contacts there.

Tito shows me all the different type of animal figures that he will send; "look here: here is another type of wood work, another edition, and it seems to sell well".

Identity:

Margarita: Can you describe how you are like as a person?

Tito: Well, I am a simple person: honest, hardworking, and religious, as well.

Margarita: Right, and can you say something about your relations to your family?

Tito: Well, there where some problems, between the families, my brother and I, you see. The problem is that I got angry and nervous, and sad, because I care about the others. Now the relations are fortunately good again.

Margarita: What do you think has influenced you to be the person you are now?

Tito: I am sure about myself: that is important. With my people, I try to have a good communication. When my daughter was here, we stayed together, and talked every day. I try to be as good as I can. My daughter Dolores was only six when her mother left us; but God gave me the capacity to support her, and get her forward in life, and if she wants to do something, to say "just go for it!"

Margarita: Yes. I remember she told me that she wanted to become a physiotherapist.

Tito: Aha, she dreamt of that earlier, but then she did not follow that dream. There were several things she wanted to do; only that she did not know how to do it. Also she wanted to learn music, and she went to Oaxaca to study, but she did not really learn much.

Margarita: How do you think that disability has influenced your life?

Tito: It has influenced me a lot. It has made me the person I am today.

Margarita: And what is your vision of disability in the future?

Tito: I think rehabilitation centres are important, but disabled people should most of all learn how to be independent there, though the centres are necessary to control the support one gets.

Tito is a reflected man. He acknowledges that disability has thoroughly influenced him, and made him into the person he is today. From the little I know about his family background, and life in his village of origin, one might suspect that he also used to be a somewhat “macho man” earlier, but that he has softened up a great deal. He says that he is sure about himself now, and perhaps that is why he does not depend so much on the “macho ethos”, which is prevalent in this environment. His family relations are important to him, both practically and emotionally, both from what he says and what I have been able to see, though he manages his life independently.

Garp and Tito’s dramatic accidents lead to similar disabilities. Their social situations before and after their accidents have nevertheless been quite dissimilar, although they seem to have a comparable socio-economic background, that is: striking poverty and little education. Their socio-cultural values have however differed. Garp engaged in illegal activities, while Tito chose lawful labour. This has given the two men different kinds of social recognition.

Garp’s recognition has consisted of fellowship with his friends and brothers, and admiration for his courage and skill to commit illegal activities, his ease in playing sports, conquering girls, and searching rapid gains and pleasures. By other people he was both feared and admired. He was feared because he was a criminal, admired because of his skill in sport, and appreciated for his ease to lend favours, both legal and illegal, and for his humour.

When I was back in 2005, Garp had made a substantial change in his own activity and being. He had become part of Tito’s religious congregation, and he had started to relate to, and also depend on, the congregation. His problem, though, was that the wider community did not actively recognise this change, and he seemed more lonely and stigmatized than ever.

Tito was in another situation. He had also gone through a very hard time accepting and forming his new self-image as “disabled”, but he gained opportunities through trust and systematic labour.

Tito now had a house constructed in one of the outskirts of Aguatepec. Here he has set up an own artisan workshop, where Garp irregularly comes to join him to work. Also he trades artisan products from other communities.

The biggest change in Tito's situation seems nevertheless to be his prominent position in the congregation. His faith has helped him progress, he believes, and now he is partly directing and organising local masses or meetings; *cultos*. This is a status that provides him with important social recognition, not only from his co-believers, but also from the fellow villagers in Aguatepec. The fact that the newly elected political leader of the village adheres to the same religious congregation as Tito, also enhances his status somewhat.

Benito

In the beginning of fieldwork I overheard a lot of gossip about Benito. I understood that he was one of the men in wheelchair who had become paralyzed due to a violent accident.

He was the father of six small children, of which the oldest and only daughter was Aurora, an 11 year old girl with Down's syndrome. His youngest son was only three years old. The whole family lived in a simple hut within the centre's area.

Rumours said that Benito beat his wife Alexandra, who worked at the centre's kitchen.

Another grave problem was that Benito did not take care of his own body, and therefore he was already getting open sores on his back, due to the constant rubbing on the skin by the wheelchair, and lack of proper hygiene. Personal care often represents new challenges, difficult to remember, for a person who is newly paralysed. In the open dining room of the centre, Benito's case was a favourite topic, and the leaders of the centre concluded that a scrutinized personal hygiene did not fit into Benito's macho image, and therefore he could not do it. Instead he expected his wife to take responsibility for him, in addition to the six children, and the work she had to do at the centre. "Such an attitude is typical here," they said.

I soon identified the man who I thought had to be Benito. He sat in a wheelchair, his legs cut off, and he seemed to like to stay in the kitchen area, where he joked and flirted with the women, and especially Alexandra. He used to sing and play with her sons, and I observed that Aurora often went to stay in his workplace in the artisan carpentry during the days.

"But isn't that man called Garp?" I asked my superiors. "No, no, it is not the same man: Garp is all over the place, but Benito hardly leaves his hut".

Later I got to meet the real Benito, and I first visited him while he was hospitalised in a public hospital in Mexico City in order to get professional help to heal his sores.

I experienced him as a quiet and shy man, not as I had thought. One reason might be that his mastery of the Spanish language was not perfect; the indigenous Zapotec language is his mother tongue. Also the fact that he had isolated himself, had not made him used neither to my presence nor to other international volunteers, except Amelie, a volunteer who accompanied him to Mexico City to nurse him. Therefore he seemed not to be able to talk as freely as I would have wanted.

When Benito came back to Palapa Papaya, he was placed in a single room in the new rehabilitation area, while the rest of his family stayed in their old hut. He needed rest and peace, officially, but off the record it was also a means to protect his family against his resentment. I went to talk to him, and asked him to do an interview.

Benito accepted, but the conversation did not flow easily. Partly this might be due to the fact that we did not know each other much previously, partly because I was a woman and an acquaintance of his wife, and I knew that their marriage was not merry. The fact that I was a Foreigner, a *gringa*; which among other things meant white and rich, while he was Indian and poor and not a native Spanish-speaker might also have influenced the setting. All these details might be used to explain our interaction in the situation, though also other personality traits influenced. Benito seems shy and reluctant to expose his private life or feelings.

Benito: I come from Coatepeque. It is part of the region of Romero. Up towards the mountains.

Margarita: Did you always live there?

Benito: Yes, that's where I always lived. I was born there, so that's where I come from. I could not leave the place until after I had my accident.

Margarita: And how did the accident happen?

Benito: Well, what should I say ... they shot me.

Margarita: Ah... and why?

Benito: There was a problem, but...

(silence)

Margarita: Earlier; did you know any persons with disability? Except for Aurora (his daughter)?

Benito: No, I did not see a lot of disabled people earlier. But after I came here, I see many who are just like me.

Margarita: And when Aurora was born; what did you think? Did you know that she had a syndrome?

Benito: No, we didn't know. Well, when she was born everything was fine, but yes; after a year, and after another year she did not walk.

And then; I brought her to the doctor, well, and he told me that she would walk soon, but he did not know why she did not walk, until I brought her to (the state capital) Oaxaca, they told me what it was; a syndrome. They told me that she would walk, but about talking, she will not talk. Mhm.

Margarita: But now she is learning to talk.

Benito: Yes, finally, now she talks a bit, more or less.

Margarita: And how do you think it is for Aurora here in Palapa Papaya? Is it different from your village?

Benito: Yes, it is better to stay here. Safer, for everybody.

In 2005 I wanted to see how Benito and his family were doing. I soon found out that they had moved away from the rehabilitation centre now, to the outskirts of the village. I did not want to go to their place unless I knew that his wife Alexandra was at home, because I never felt too confident with Benito.

I heard Alexandra works in another village, in a more developed tourist area, and she didn't come home until quite late at night. I definitively wanted to go see them, but I did not know exactly where to look, and I feared I might not be able to see them. Then, one night towards the end of my stay, I got the chance to go to their house. Timo would accompany me and help me find the place, as I did not know this part of the village, which is currently being populated.

We find the place, at last. Timo has been using his wheelchair on the road, but now he needs to park his chair in the bushes and use his crutches to get to Benito's place, about five hundred metres away. How can Benito manage here?

When we arrive around half past nine, the family has already spotted us, and they seem happy to see us. "What a miracle", Alexandra laughs at me, and we greet each other heartily. Aurora has grown into a teenager, and she seems shyer than she used to be, which is not strange, because we haven't seen each other for a long time. After a little while she begins playing with my hair, and she stays close to me as we sit down and get some water to drink.

All her brothers are going to school now, but Aurora had to quit the special education school in Comintla, because they didn't manage to get her there, her mother says. "But she has got some exercise books, and she loves to play that she is at school." I ask them how they feel here, and they smile and say they are good: at last they have their own place. Alexandra says she can take a *colectivo* just down on the road in the morning to get to work, and that she likes her work. Also she gets some time with her family in the mornings, because she doesn't need to be there until 10. She comes back around this time at night, and occasionally later, in the tourist season. "Also I got every Monday off, which also is the market day in Comintla, so I usually go there to shop," she says. "What about you?" I ask Benito. "Good", he says; "I look after Aurora in the days, and then I get the boys some food when they come back from school." "But the pathway to get here is awfully difficult to access," Timo says: "how do you manage?" "Well, I don't go out much," Benito answers: "and if there is a special occasion I can get some help."

Benito seems happier than I have ever seen him before, and this is, at least partly, due to their new housing conditions. He never seemed to like living so close to strangers as one does in Palapa Papaya, and he never made efforts to turn strangers into friends, as the rest of his family did. Then, he had yet to come to terms with his disability and his situation, which became detectable by the fact that he did not care about his *llagas*, or sores, which developed rapidly on his back at that time.

It takes time for anybody to accept a sudden bodily or other change to his or her being, and Benito, seemed to be ashamed of showing himself publicly.

Now Benito seems to have accepted his disability to a greater degree, and he seems relieved to not being forced to meet people in public. However, it looked like the ethnographer's sudden visit cheered him up. Not many people passes by his house normally, as it is virtually on the border between the community and the woodland.

Benito is dependent on his family's continuing support, and also his social recognition depends on them. While he himself is not a very public person, his wife and half dozen children nevertheless enhances his social status. The fact that his wife is the mean economic, social and cultural provider for the family, and works outside the home all day creates ambivalence as towards Benito's own position. While the family lived at Palapa Papaya, Benito's anger and jealousy became public, as the others who lived there could hear his wife crying when her husband hit her at night. Alexandra was indeed surrounded by rumours about affairs, but she maintained that nothing was true.

Tomas

Tomas is a young man who works as coordinator for the volunteers at Palapa Papaya. He is one of the many male victims of social violence. He got a spinal injury as a result of a fight when he was 19 years old, and here I want to show his strategies to overcome the helplessness he and his family experienced afterwards, and the combination of identity traits and circumstantialities (cheer luck) that made him choose to regain control of his own life, and rebuild his self image and acceptance.

I got a very good first impression of Tomas when I arrived at Palapa Papaya early one morning in the beginning of November 2001. When I saw people get out of their huts inside the rehabilitation centre Palapa Papaya, where I was to spend the next half year or so, like a quarter to 6 in the morning, I was filled with curiosity. I soon got to greet people, and found out they had been waiting for me for several days.

Tomas came forward to give me a warm welcome, and we kept on talking and drinking café con leche until people gathered in the *comedor* (diner) around 8 o'clock. He told me he had had an accident 6 years ago that had left him dependent of a wheelchair for the rest of his life. Now he was 25. He had spent the first three years after his accident inside his family's house in a steep village near Comintla, until he came in contact with Palapa Papaya, which has become his fortune, he said. In the beginning, though, he had not wanted to integrate here, but through insistence especially from Bill, a former North American volunteer and friend, he got motivated.

While he lived with his family he had been totally dependent on them. They did everything for him, “*yo, no’ mas comi*”; “I didn’t do anything more than eat”, he tells me. He was so weak that he was not able to lift himself when he came to Palapa; now he rolls much faster than I can follow. After some months at the centre, when he had undergone intensive training, that is rehabilitation; the administrative staff asked him to stay and work at the institution, something that he accepted. Earlier; one of the volunteers used to be in charge of the coordination of other volunteers, but now Tomas does this work, plus communication with visitors.

I ask him whether he thinks it is better for people in his situation to stay in a sheltered place, and live together with persons who have similar experiences themselves, and he says it is a lot easier. Now, he feels independent, he states, and he is very satisfied with doing something meaningful, both for himself and for others. The main problem though, he think, is the lack of physical facilities, for example for wheelchair users in nearby towns and villages, for example in the state capital Oaxaca.

After some time my attitude towards Tomas changed. I felt he was all too *macho*, and perhaps even a bit *machista*. He had a tough image, which is perfectly normal here around, his way of behaving resembled patronising, and it seemed that he liked *mandar*²⁵; ordering. It had much to do with the fact that he was my “boss”, as coordinator for all voluntary workers at the centre, who were around 10 young people, both Mexicans and foreigners. Tomas was controlling our work and leading the meetings every week where we planned our work, but the meetings with Tomas were seldom open for critique or evaluation. Thus for us voluntaries, the informal chatting that we did every day felt far more important than these meetings.

When I returned to do my second fieldwork, I was nonetheless able to forget about old disagreements, and do a truly attentive interview with Tomas.

We meet outside the old ‘Casa Cabróna’, the oldest building for volunteers, where Tomas have been training weight-lifting until I arrive.

Independency through integration:

Margarita: I would like to know how you feel now, compared to 4 years ago, for example.

²⁵ *Mandar* is a Spanish verb that means ‘to command’ or ‘order’ in these circumstances. ‘Mande’ – which means ‘order me!’ – is an expression which is much used in Mexico. When a child or a subordinated person is addressed by an adult or an higher ranged person, the first response is almost always “mande”, which implies that the child or the subordinated person is ready to fulfil the other person’s order (or wish).

Tomas: Well, now I feel quite good, I am super integrated in society, work, and everything else. The change has been total, hasn't it?

In the beginning (after my accident) I was totally dependant on my family; my parents and my siblings, and now it has been totally different, now it has been I who am integrated; I go out, I travel, and I work without problems, now I don't depend on some other person, but rather I am independent.

Yes, it is a great advantage, isn't it? Because when you acquire a disability and you don't know how to confront it; you are not prepared, more than anything, to confront disability, well, it's ... (difficult), if you don't know what to do, you see? But when I came here, 7 years ago, I started the rehabilitation process, and well; the change has been substantial.

I don't limit myself at all, you see? To the contrary; everything that I want, I can get it, and I look for it, you see? I look for a way to do things, even with my disability, I don't use it as a pretext; "ah, the case is I've got a disability, and I cannot," you see?

To the contrary; to me it is a pleasure discovering in what way I can confront life, you see?

Margarita: Ok. I'll take a little look in my guide. Yes, here it is; although I've got an impression, based on my memory, of how you are as a person, I would nonetheless like you to describe a little bit; how are you as a person?

Tomas: Ok; well as a person I describe myself as very active, as a person able to solve whatever problem which presents itself for me, like how can I explain it for you; the disability that I have got, I bear it with me, you know, and I can't evade it, so I feel I am an active person, integrated in society, when it comes to work, friendships, and everything else, don't you think?

So that's how I could picture myself; active, just as any other person, you see?

Then for me right now there is no obstacle that makes me say that I can't do something because of my disability. No, to the contrary; I feel that I am a person equal to everybody, in everything, when you speak about work, and everything else, I feel that I have demonstrated this (independency) here, with the responsibility that I have got here (at Palapa Papaya). It has helped me a lot to discover myself and my capacity, you know.

The responsibility that I assume, it is because I have always liked to be responsible, you know. I have always liked to really assume the commitments that I am given, whether it is in regard to work, to my family, or to myself.

For example; I am a cheerful person.

But also; in questions in regard to work; if something disappoints me, I will assume my responsibility, as yesterday, you noticed with Garp: Garp is a person who is not very trustworthy here, that is because he has stolen things in the carpentry, then sometimes I show myself hard. I am talking about my character, you see? But I feel that this has helped me to progress, and to confront a disability one needs to have character, you know, more than anything else.

A disability is difficult to confront, and even more so in this society, which doesn't even have a clue about what disability is. Then it is quite difficult; confronting it, but if you don't, you won't get ahead, you know.

There might be a lot of persons surrounding you, professional specialists; doctors, whatever; but if you don't have that initiative yourself, if you don't have that commitment with yourself...

Margarita: Well; you'll get stuck where you are?

Tomas: Yes; there you will dwell, waiting for everybody doing everything for you, but if you are not willing to do anything for yourself, you will never succeed, and I think that this is what characterises me; my character, what is inside me.

I fight for myself, and also for my family, because now I have also got a commitment with them.

Thomas is extremely explicit, and he seems proud of how independent he has managed to become. Independence from his family, that is, because he does not consider his relationship to the rehabilitation centre as dependence, and even though I see that this relationship also has got many characteristics of dependence, what makes it qualitatively different is the fact that it is voluntarily formed.

Margarita: Yes; and how have your relations to your family been, and how are they now?

Tomas: Very good. It is actually not until now – that's why I mentioned to you that I've got a grand commitment with them now, because you know; with them things have been superb. They've never let me down, from the moment that I acquired the disability, and then there were like three years that I was totally dependant on them; I could hardly do anything, by myself, because I wasn't prepared to confront my disability, you see?

I hadn't discovered my own qualities then, and I couldn't discover them until I came here, and then put them into practise, you know.

Then this has been great, because now I feel committed to my family.

Because in the moment that I needed it, they stayed with me, and now I try to pay them back, staying with them, and helping them as much as I can.

They are my family, you know, so I'm content.

Margarita: Yes, and one more question; do you feel there is equilibrium between your own forces and the hopes you have for life, and what other people think?

Tomas: Well; my hopes, or most of all my challenges, they are entirely mine, and whatever people think about me, that I can't do something, for example; I will prove them that I can. And here at the centre I feel that people believe in me, because I have proved some things.

Tomas strongly values independency, and he emphasises that here at the centre he feels independent, because he feels people believe in him. When his accident happened he was still a teenager (19), and from what he has told me, it seems as he could not escape from the hierarchical child-parent relationship while he lived with his family. Parents often have a tendency to overprotect their children, and this is probably a more common dilemma than maltreatment or neglect, especially when it comes to children with disability. At the centre, to the contrary, Tomas is treated as the grown up man he is. Here he has received responsibilities that he is able to accomplish, and he does it with a lot of engagement. I see this as his way of searching, and getting, respect. Although his experiences at the centre, during seven years, has made him highly familiar in the setting, and Palapa Papaya now is his home, the centre still does not represent the same sort of backstage as his parents' home in mountains. When some of the other workers and persons linked to the centre do not behave in observance with the centre's rules, he has got and takes the responsibility of obliging them to. He explains that this is easy for him to do, because it feels natural, and is part of his character. Tomas seems thus like a perfect subordinate leader, as he almost seems to have the credo of patronage embodied.

My point with these four contrasting examples is to show that strategies for searching for respect and recognition are multiple. Such strategies are shaped by choices and circumstantialities. Individuals often make choices without reflecting too consciously. We are following cultural and personal patterns, which have become habitual. For a survivor of an accident or illness which leave the person with some sort of disability and physical loss, the inability to use one's own body as before will quite obviously lead to personal and social disturbance and some sort of suffering.

Later one must try to restore own self-image and employ strategies for social recognition. One's background and social capital will influence the patterns one makes. The four men in this chapter are using different strategies in their search for respect and social recognition, and they are attaining different goals. However, they all seem to have been embracing a cultural preference of risk-taking.

Risk-taking is culturally meaningful as a way to express manhood in the region where I studied. A parallel can be drawn to Frank Bruun's study of disabled war-veterans in Nicaragua. They were presented as heroes and martyrs during the Sandinista rule (1979-1990), a period in which "Nicaragua was the scene of a struggle to change the identity of disabled people" (Bruun, 1995:196). In this period the Organization for the Revolutionary Disabled (ORD) was the largest and most influential group of disabled people in the country, and Bruun observed that also other disability organizations employed similar strategies in order to redefine their social status, for example by promoting sport-stars with disabilities. "Here the hero as a symbol is of real value because heroism can be connected to the values of machismo," Bruun argues.

The four men presented in this chapter had all engaged in violent risk-taking, and although they now could be labelled victims of the same practice, they actively sought strategies for respect, which also included further risk-taking.

Chapter V: Strategies to overcome stigmatisation

As I have pointed out previously, there are multiple ways to overcome stigmatisation related to disability. What I focus on also in this chapter, because it arises as a crucial concern, is the quest for social recognition: the establishment or restoration of self image. The men treated in this chapter are using socially approved strategies in their search for social recognition and respect, where their background and social capital influence the strategies chosen. Goffman (1963) stressed the *relational aspect* of stigmatisation. One's eventual social stigma is not an onerous personal attribute, but a relationship between an actor's interpretation and expression of such an attribute - or marker of difference - and other people's responses toward the actor. Such differences might be publicly concealed, or militantly expressed, marking the categories discreditable, the ones who hide aspects of themselves which would have put them in a bad light had 'it' become publicly known, and the discredited who are visibly marked or known, and who thus must accept being placed as deviants of some kind. For none of the persons with disabilities which this paper concerns, concealment is an option, as the nature of their disabilities, which are mainly physical, and always visible, are parts of their physical being, and not possible to escape.

Jimador: Getting a disability can be seen as a grand experience in life

Jimador was 37 when I met in Palapa Papaya. First I met his old mother, though, and then his young wife, as Jimador could not abandon his room. He stayed there for a month, in order to receive rehabilitation and learn how to manage a wheelchair. He had suffered a motorbike accident six months earlier, where his spine was injured. His mother and his wife stayed with him to support him, and in addition they carried out different practical tasks at the centre.

"Why must destiny be so hard to us?" an old woman was exclaiming one afternoon when I came to the centre's lavatory to wash my cloths. The lavatory is an open hut with ten solid washing places in two rows opposite another. The old woman was Doña Dominga, Jimador's mother, and she was crying out her misery to Doña Olga, who was employed to do the laundry for the young permanent patients.

Doña Dominga was addressing God the Almighty and the heavenly powers, but she also asked Doña Olga and now me if we knew someone around here who could deduce her future. Neither Doña Olga nor I had such contacts, but why did she want to know her future? I asked. Then the old woman started to tell us about her son who had just suffered a traffic accident, and as a result he had become paraplegic.

Doña Dominga: Now he is just sitting there, or lying in bed. I hardly see a reason to keep on living. I would have liked to know whether there is a hope for him, or not.

Margarita: There is always hope. I think it is better not to know what is awaiting us in the future. I can tell you something I experienced myself, as I also suffered a grave traffic accident, almost ten years ago. If I had known about the accident and all the problems I had immediately after on beforehand, I don't know. I might have chosen not to live through it. However, now I have recovered a lot, and I am actually glad I got the experiences I did, even though I never would have chosen them of my own free will.

Doña Dominga: Oh, I am glad you told me this. We will manage as well! Wouldn't you come to visit my son some day? I think Jimador would have liked to talk to you.

Margarita: Yes, I would like to, and perhaps I might interview him: I am doing a study for my thesis at the University in my country here at the centre.

A couple of days later I met Azucena, Jimador's wife. We sat down and had dinner together in the circular *comedor* in Palapa. Her mother-in-law had mentioned me, and we soon got into confidence. We were about the same age, and the conversation flew easily. I told her I would've liked to meet her husband, and perhaps interview him, as I need to collect information for my thesis. She thought that would be fine, and I picked up the little bag, with my tape recorder, before I followed her into their hut.

Margarita: As I told you, I have some trouble with handwriting, and therefore this tape recorder is very convenient.

Azucena: You have got problems with your hand? *(She takes my right hand)* It is shaking, isn't it?

Margarita: Yes, that's right, though I can use a typewriter, but it is heavy to carry, you know. With the recorder it is easier, and I don't miss anything.

Azucena: I see, and later you can find back what you've said?

Margarita: Yes: afterwards I listen to the tape and write it down.

Azucena: Ok, now I think I will let you two in peace.

The three of us start discussing whether Azucena should take part in the interview as well. It would certainly be valuable to get both husband and wife's points of view, but Azucena decide it is better that Jimador and I are alone. She takes a walk outside in the meantime, and Jimador starts to tell me about his accident.

Jimador: It happened on the 8th of August last year. It's just 6 months ago! I was riding my motorbike, when there appeared a youngster in the opposite direction. I stopped my bike, to let the boy have a free lane to pass. However, the boy rode a crazy horse, and he bumped into me when he passed. It happened around seven in the morning, when I was on my way to *Contreras*, a neighbouring village.

Just behind us came a pick-up with some señores, and two of my brothers were there. They picked me up, and returned to Morelia. There they brought me to a clinic. I think we stayed there like half an hour, before they brought me to Jinotega, the capital. There they took a radiography of me, and the doctors said they couldn't help me: We should better go to Acapulco, or just go back home, because I wouldn't reach Acapulco alive, anyway. Well, my brothers brought me to Acapulco, and we arrived at the General Hospital at seven in the night.

My wife travelled with me from Morelia, and then my mother caught up with us in Jinotega. From there we were my mother, my wife, two of my brothers and me. And we reached Acapulco.

Margarita: What luck that they were with you!

Jimador: Yes, really fast. As they were going to Contreras, just like me; thus in Morelia they called my mum who was on her ranch, and she came quickly to Jinotega. But in Acapulco they did not operate on me at once, I was there the 8th, but not until the next night they operated on me, and everything inflated too much. I felt I couldn't see anymore, and hardly breathe. Then I fell into coma: I didn't wake up from the anaesthesia. In that hospital I stayed for two days, and on the third day they moved me, still in coma. I had been operated in a private hospital, as they didn't have a place for me at the General Hospital. After the operation, though they brought me back to the General Hospital. I stayed in coma for 20 days.

Everybody thought I would die, that I wouldn't last long, as I was severely injured. Three ribs were broken, one lung was hurt, and my breast was half open. My right shoulder was fractured, and my neck had broken. The sixth vertebra was smashed, and the fifth was fractured.

But they took out some bone from my pelvis, and transplanted to the sixth vertebra. I stayed in Acapulco for two months: August and September, and the 10th of November I was back in Morelia.

Jimador is a reflected and balanced person. From the interview we did, and the few observations I made at Palapa Papaya, he seems to already have accepted the disability that he has just acquired. This man does not come from such poverty as the majority of the population in this area. This might be a contributing factor to his feeling of some control over the situation.

A person without economic resources might to a higher degree experience a lack of control in his or her life. He or she is dependant on other people's likings and circumstantialities. In a situation of crisis, where one needs professional medical help immediately, these persons are dependent on their social capital, particularly when the social health system is fragile.

Right after Jimador's accident he was however driven to different hospitals by his own brothers. The fact that his brothers were the first to come to the place of the accident was coincidental, but the fact that they had their own car, shows that they are part of an economically better-off part of the population. Also, the fact that they were not convinced by the first responses they got, and therefore searched out other hospitals after they were given no hope at the first one, is an indication that they are well informed persons. Firstly, because they know about different hospitals in the area, secondly, because they understand that it is imperative to get medical help as soon as possible and thirdly, because they have the means to use existing possibilities. Their reactions are acts of desperation, but they are channelled well into a formalised strategy.

The will and ability to insist indicates that they are used to be in charge of their lives. They are used to *mandar*, to command, probably, and at least partly, as a result of their upbringing. *Mandar* belongs to their *habitus*. They do not accept being cut off, as commanding is part of their *cultural capital*. Perhaps

this cultural capital and the experiences these brothers embody, was one of the reasons why Jimador was still envisioning a good life, despite the fact that he had acquired a physical disability.

Cultural and social capital is not the same as economic capital, but the forms of capital often interlink. In this study I draw primarily on Bourdieu's development of these concepts (1986:183-98). Every one of us has got social and cultural capital, and each one of us will try to specify this competence to meet our interests and needs. Persons who have a somewhat high amount of cultural and economic capital have, as point of departure, better possibilities of getting professional education, something that will often enhance also their social capital. Persons who are economically poor and without much formal education, will often acquire specific knowledge that help them survive and manoeuvre in a specific environment, knowledge which could hardly be learnt at school. This is also cultural and social capital, and the ingredients can be seen as what forms Lewis' notion of culture of poverty. Jimador, however, does not belong to the desperately poor, and he has acquired both formal and informal education as part of his cultural capital.

Jimador: Everything is very recent. Then after three days at home I couldn't stay any longer, because I started to feel very bad, and I got sick. There is another little hospital close to my home, in *Manantepec*, where I stayed for 15 days. Afterwards I returned home, where I stayed for about 15 more days, before I came here to Palapa Papaya. When I came here I was still sick, my lungs, and here on my back I've got a sore, and thus I cannot go to therapy, because of the wound. When I came here it opened up and got deeper. Thus the doctors said they can't work with me, but I hope I'll be better soon, naturally I will try to heal, but on the top of everything I got pneumonia!

Margarita: Did you know any persons in wheelchairs or with other disabilities earlier?

Jimador: No, I didn't, but I have always liked to talk to people who are sick. I have liked to help them with whatever I can do for them. But I never had any intention, or pre-intelligence, of riding a wheelchair myself. From now on I will observe sick people in another way. Honestly: I never visited a centre for people with disabilities, or a medical hospital, until now.

And that I suddenly should be one of these persons myself, me: who never have been bedridden. I used to be very active: riding horses, my motorbike, or my car. I used to be hunting and I was painting. I was exporting things to Mexico, and I valued my own activity. I liked sports: weightlifting, golf, so many things, and most of all basketball. I used to play basketball like an hour every day, and one hour of weightlifting, at 5 o' clock in the morning. Then I played basketball in the afternoon, from 6 or 7. Throughout the day, I went to do my tasks on the fields.

Margarita: Did you always live in the same place?

Jimador: Yes, in Morelia. I never travelled around much, and even less after I married Azucena, which is a long time since. Prior to that I did travel a bit; I used to come here to Puerto Santo, to Nisatulco, or Aguatepec. I was always in this area, but I never came here to Palapa Papaya, but here it was always! Puerto Secreto, Jinotega, Acapulco, Mexico, or Michoacan. I visited everywhere, but then after I joined Azucena, I changed: I didn't go out anymore. I didn't drink anymore, nothing, and I liked it in that way.

I've got four children. They stay in Morelia now, with my aunt, a sister of my mum, and with a sister of Azucena. They've come here to visit.

Margarita: Yes, I remember seeing a baby.

Jimador: Yes, now my oldest daughter is 9 years old, the next will be 5 soon. Then one is soon 3, and the little girl is just 7-8 months. Although the oldest one is not hers, but Azucena took her over while she was little. Thus she calls her "mum", and everything.

I had other women... I've had four women with her. But now I don't want others, I love her and nothing more! And I love her deeply.

Margarita: You haven't been in the wheelchair for long, but have you noticed people's reactions towards you as a wheelchair-user?

Jimador: Well, I have tried to take a walk in my wheelchair, but to be true: that gives people panic. I would say that it produces embarrassment, even between friends, because a lot of people look at you in a different way.

One has to accept. Now we have another kind of rhythm, we have to revise the way we are today, and catch the world from this point of view. It is another fringe of living. Plus another attitude: we cannot keep on the same as before. Perhaps we can keep our old ideals of thought, but we cannot keep on with the same physical activities.

We need to modernise ourselves, to change. Try to act differently, you see? And make a change in our life. Whether we want to or not, and finally we should deal with disability as a real concept, and with pleasure. We should try to imply pleasure within us, as a necessity, and most of all: realism. Get through in the reality, were we keep on living, and smile to life!

Jimador wanted to accept the turns that his life brought him, for better and for worse, but not passively. His background, his cultural capital and personality seemed to influence him to take responsibility of his life situation. He believed that he was the one who must adapt to the realities, and not the other way around. Differently from those who are immersed in relationships of economic and other dependence, Jimador trusted, based on his personal experiences, that he himself could control his life.

Jimador: That is a decision: Try to confront life courageously, with piety, with laughter, with tenderness, and feel, or think, that life goes on, that it isn't finished, that we can still live it, but in another way. Well, we have decided to keep on fighting, and try to make a future for our kids. We just need to find a way to do it.

Margarita: Do you think you will keep on living in the same place as before?

Jimador: Yes. Though we are also thinking about looking at some contracts that we have got, and perhaps move to another place... But I think it is better that we don't, because my mum doesn't want us to. As all her children live around there, and she as well: I think that she would feel very bad if we left.

Margarita: But you yourself; where were you thinking about going? Here to Aguatepec, or another place?

Jimador: We were thinking about going to Puerto Secreto, or here to Puerto Santo, or even to Aguatepec. But I think that we will stay where we are. Because that is where our family is, everything is there...

At least if we can't sell... We do have some money in cattle, and if we could spend that and make a change in our life, we could settle in a village and make a commercial carrier. But honestly, I am not made for commerce, I never liked that kind of work, and I am not a professional in commerce. I was dedicated to my activities. The little bit of expertise that I have got is on the field, with the cattle. Agricultural work is what I can. I like the field, and most of all I like cultivating fruits.

I was transporting papaya to Mexico City, but look what happened to me! Now I have been working for 6 years, wholeheartedly, that is.

Margarita: I see, and what do you think about the accident?

Jimador: I say that it was a simple accident, though I keep on thinking if it was God's revenge, if it was just what I deserved, because I had too much trust. You know, I could have punched myself off the motorbike before this comrade crashed into me. But I trusted. I thought that he would turn right, and not touch me. But that didn't happen; he didn't make it, and all for nothing!

Margarita: So you remember well what happened?

Jimador: I remember everything! I didn't have much time, but I had a second to slip away from it, and I wouldn't have crashed, but I trusted. Look how that came out, the confidence! A very expensive blunder...

Margarita: What happened to the other guy?

Jimador: He fell, nothing more, but he wasn't hurt. He is my brother's son.

Margarita: Really? And how do you get along now?

Jimador: Well, I always thought that as a brother, he would support me some day, but he doesn't. He never helped me, and I find it unlikely that he ever will. Though I don't have bad feelings for him... If it had been somebody else I would have reported it to the authorities, so he would have to pay my spending, but as he is my brother's son... From I was a child they taught me that there is a special relation between brothers... No, I don't want to do anything, I don't want to plead. If he had conscience; voluntarily; physically or morally; he would help me. But he doesn't.

Margarita: It seems like the accidents happen more at home, between family and friends.

Jimador: Friends and family, yes. Sometimes we think that such things are the devils work. But we don't have anything in concrete, but we call it accidents...

The relationship between Jimador and his eldest brother seemed not to be as smooth as the ideal. If there had been someone else who had caused the accident, Jimador says that he would have reported him or her to the authorities, and the responsible would have been forced to pay him, as victim, the extra costs he had. Since the victimiser was his own nephew, Jimador did not want to include the authorities in the case. He said he did not want to rankle because of what had happened, though he thought his brother should have been conscientious enough to voluntarily help him in the situation.

Rather than blaming somebody else, Jimador blamed himself for being as naive as to trust blindly somebody else's way of action. When he looked back on the accident he highlighted the passage where he could have acted differently. Why didn't he throw himself off the bike when he saw the horse coming?²⁶

²⁶ This is a typically individualistic, or "western", way of explanation. Nonetheless, in most situations a multitude of different ways, or choices, of explanation, as well as of action, do exist parallel to each other. This is true in all places of the world, though the actual flexibility and multitude of choices depend on the circumstances and the cultural capital of each actor. In typically "western" countries, we tend to look for possible "rational" explanations for phenomena and actions. In my own situation I think that my mother might have blamed herself for lending me her car on the day of my traffic accident. This was an individualistic way of explanation, probably resulting from a feeling of guilt, which might not be explained rationally. It is an emotion which is culturally dependent. When I woke up from my coma I did not blame neither her nor me, but rather the external traffic authorities who had evaluated the conditions and not found reason for sprinkling the roads that day. That way of explanation seemed rational to me, but not individualistic, rather culture bound. In countries with a strongly regulated state machinery, we seem to tend to blame the authorities. When I fully won back my consciousness, months later, the whole

Margarita: Though you can take your new situation as a challenge, as well. Now you suddenly get some new limitations in this play of life! But you can keep on playing, that is living.

Jimador: Yes, because we can take it as a grand experience in life, which we can communicate between the others. It is like a school, physically as well as morally. You learn to value everything in life, large or small. You might realise that it is not only the world where you used to live yourself. Rather there exist other worlds which one can enter in the same life, but in another manner... For me, what I live now is another world, although we live the same life. But we should take it in another manner. We can't keep on unchanged as before.

As Jimador seemed to have accepted the consequences of his accident, he was also able to see his new physical limitations as a challenge, and not only as a sorrow, as his mother. This might have something to do with the freedom he experienced in his life until he married, about six years prior to the accident.

It seems like Jimador had been allowed to be young and reckless for such a long time that he had become fed up with that kind of life. Now he was approaching his forties, and he wanted to live a quiet family life, and he saw that this was possible, despite the fact that he had become dependant on a wheelchair. If the accident had happened 10, 15, or 20 years earlier, it might have been more difficult for him to accept his bodily change, and the changes he must subsequently make to his life.

Jimador: We live the same life, but our world has changed. Or: we live in the same world, but our life has changed. Change, and there is nothing else to do than throwing yourself into it. Fight. Try to get out on the other side. Decisions and more decisions: for each one of us to take. But it's not only bad, it is cool also! Because in situations like this, it is like your mind develop more.

accident was envisaged as an unlucky circumstance, where my own lack of experience was decisive. This is a rational and individualistic way of explanation, though it does not treat any reasons for the unlucky circumstances.

As a comparison, I will mention *Pancho's* reaction when his cousin had died after falling down from the top of a palm tree. Without further considerations, he blamed the tree, which he condemned in strong words. A part of the core in the top had been rotten, and that is what failed when his cousin had hit it for loosening nuts. The flaw was applied to the tree, and it was never mentioned that the cousin should have been more observant or careful. What was mentioned was that his cousin used to be a *cabron*; a devil (literally; a buck) at cutting down coconuts, in his youth. It was not mentioned that now he might have been a little out of shape, a little overweight, and a bit drunk, it was that goddamn tree! This is not an irrational way of explanation.

The same *Pancho* would blame *el aire*; the air, for his son Timo getting polio as a baby. Timo accepted this explanation without asking his father to specify the content of the word *aire*.

Traditionally, in this environment, it is believed that the air is animated; it is full of life and spirit. *El aire* is potentially dangerous, especially to small children, because they are more easily influenced by supernatural forces, and they might be stolen or moved. Habitually *el (mal) ojo*; the (evil) eye and *el (mal) aire*; the (evil) air are used almost synonymously, though *el ojo* is to a higher degree personified.

Then *el aire* is understood as an animated malevolent force. Timos parents said that a *mal aire* passed through the city during the days when their son got infected by the polio(virus), and that that *aire* contaminated several children in the area on that time.

Jimador also had a rational explanation to his accident. He would say it was a simple accident, he said, but at the same time he couldn't help wondering whether it could have been God's revenge for some immoral action that he had done. But most of all he thinks that it happened to him because he was uncritical in the situation. So he explains the accident rationally, using an individual mode of explanation, while he does not exclude the possibility that it could have been a God's revenge, that is; he is also open for a religious explanation.

One is obliged to learn. Learn from life: how to use other methods, which work better for you. And we should learn to share with the entire world, all the persons who surround us: to comprehend them and make them expand, in whatever way! Because almost every person has his or her own way of being, and we should learn to understand the other, and share what is good for her. For us, the disabled, it is positive to learn and understand what surrounds you.

I found it quite surprising that Jimador spoke about “us, the disabled”. That showed that he had, to a high degree, accepted the disability that he had just acquired. The setting also made it easy for him to launch such a statement, because of the rehabilitation centre that surrounded us, and the fact that I, the ethnographer, also drew on my own experiences as disabled. Jimador says that we the disabled should learn to understand the world. That is a quite daring statement, as in disability discourses it has often been highlighted that the outer world is the obstacle, and that what is important is to make them, the able-bodied or non-disabled, understand the point of view of the disabled.

Jimador: My mother talks... It's like she's the disabled one. It's difficult: I've got four children to maintain, and they are still very small.

Despite of his overall positive attitude to life, Jimador was also worried about the future, for how the family were going to manage economically. Nonetheless, his mother seemed to be the one who worried the most.

Jimador: Well, now I have evaluated myself a bit, and I have realised who I believe myself to be. But my mother, I see that it takes her more work than me to accept everything. As a mother, it is harder.

Me, at least I can say to her; “if you want to cry, please cry, or say goodbye, pardon me: I know I've become a genuine prisoner.” I only ask for a little ray of hope, to survive. I hope to find a way to work so I can maintain my children and my family, and: I give her the right to choose. Most of all for them, for my family, I have been fighting during these last 6 months. Without them I would have died. But I can't leave my children so young in this world. They have much left that I would like to follow. That is one of the reasons that have motivated me to keep on fighting. Fighting against death.

Another thing is that my wife has helped me a hundred percent: She has lifted my spirit. I think that if it hadn't been for her, then I would rather have died. There were occasions where one would want to die, but she has said: “you can't stop fighting! You have got to fight, you have got to live! You have got to get through this. You can't be capable of leaving us, because you are the father of your children, of our children. You have got to help!” And that lifts my spirit. It makes me prepared to fight, to survive. And thanks God, and thanks to Palapa Papaya, now I've already recuperated a lot.

Jimador saw that his mother was struggling more than him to accept the accident that has happened to her son, and consequently the whole family.

Then he had also expected his wife to rage a bit, but she did quite the opposite: showing patience, love, care and understanding. She also reminded him of his responsibilities to the family, and especially the children. That is a statement of trust, contrary to what many other persons with disabilities experience.

Often efforts to help are also acts of overprotection, which ends in permanent relationships of dependence or they are experienced as markers of difference/domination.

Jimador: I have recuperated a lot. Every doctor I meet asks me how I have done it. Who am I to survive so many fractures, in the thorax, in the back? Every doctor leaves me astonished with what they tell me: that they have not seen any human who can live with the kind of fractures that I have got. I tell them that I don't know. Only God knows why I am still kept alive. I don't know what awaits me. What will happen, or why?

Now my fractures have already healed a lot. What keeps on hurting me is the fracture I've got here high up in my breast, and the shoulders a bit, but that is less now. Earlier I couldn't stay like this: I always had to lay face down. That is why I got these scars, as I couldn't move, because everything hurt. But I am determined to go on fighting.

Margarita: How good. Do you think you will live together with your extended family in the future?

Jimador: Well, I have said to Azucena, my woman, she is very young – not yet 23. I have told her that if she doesn't feel good about the situation I am in, I can let her have her freedom. I don't want to sacrifice her: I don't want her to stay with me and have a bad time. Perhaps she can do something else, have her own life. But she rejects my position, she doesn't want to. And she feels bad about me even making the proposal, and she tries to evade it. She tells me it is not obvious, but she wants to stay on my side. She wants us to see our children grow up together. My mum; well she has been here with me now, and I feel that she will always stay with me. But when we get back home to Morelia, she will probably go to her own ranch. She will go to her ranch, as she lives with another son.

Although I imagine that she will come to see me, perhaps every two or three days. And the longer she stays with me now, the better. But as soon as I am better, she will leave, if she doesn't change her mind!

And yes, I think that I will go on with my wife, further. If she doesn't change her mind.

Jimador's relationship to his wife seemed to be harmonic. From what they said, and how they acted, it seemed that they really love and care about each other. At the same time Jimador recognised that he could not take her for granted.

Jimador: Well; you have to learn from what life is. I can give her a little for her needs, and I will do it with pleasure, as most of what we earn is for our children. But there she starts crying, and I don't know what to do.

Jimador: I have always liked to speak frankly, with sincerity. And in this situation I try to be the same. I don't want to become another person; and I don't want to lie. I never wanted her to exist only for me.

I tell her that only when you give something out of love, it is good for you. Everything returns to you. Knowing that she stays with me because she loves me, motivates me to improve my own situation, and fight. Most of all it is hard work, to try to let her and my children live well. I will do everything that is possible for me: I can behave every day as if it was my last, and I can work hard for you, as if I would live only one year. I don't know how long I will stay alive.

Margarita: What would you have done if exactly the same thing had happened to Azucena?

Jimador: I think that I would never leave her. I would try to behave as sweet as I could with her. Loving, try to make her feel good, make her feel loved. Never hurt her, and never stop loving her: never ever make her feel bad as a woman; never make her feel bad among others. She would always be my beloved woman, in love, in sweetness, treat her with all the sweetness there could be. Absolutely never propose to be unfaithful to her. As a man; if my situation as a man,

sexually, would oblige me, I would try to do it in faraway places, on workdays, but absolutely not so she could get to know about it, because that would be to hurt her forever. If she would have wanted to try (to have sex with me); I wouldn't wait. I think that I would've been more content than ever. Because for me; I wouldn't feel like a man doing it (with prostitutes). And I would never forgive myself if I were to hurt her heart in that way. If she, as woman, could please me once a year... (that would be enough).

Listening to Jimador describe how he would have behaved towards his wife, if she had been the one disabled, was touching. I believe it also reflected the way she was behaving towards him. However, in the end he admitted that despite of everything, he might have gone to other women, to get sexual satisfaction. This would have happened under absolute discretion, not to hurt his wife's feelings. He would see infidelity in such a situation as a disloyalty that his wife did not deserve to know about, though it might nonetheless have been something which he, as a man, would have to commit.

At the same time as Jimador illustrated how he would have treated his wife, if she had come up in the situation that he now faced, he acknowledged her choice to leave him, if she wanted to. He did not want her to stay by his side because of pity.

Thus it seemed as he had one ethical norm for himself: to stay with her no matter what happen, although that might imply some necessary, but shameful and secret affairs; and another rule for his wife.

Opposite to what would have been the case for him, she now had a reasonable ground for leaving him, he admitted. Why was that?

I think that he was afraid he would no longer be able to satisfy his wife sexually. It might also be that her right to walk away was something he just said, in order for her to insist that she stayed with him out of love, and not because of plight. Was he stating her right to leave, so that she should not consider an affair outside of marriage, or was it perhaps the opposite? Because as long as one does not find out about an affair, it doesn't hurt, following his logic.

Then, one can also say, and feel, that love is an obligation. His wife Azucena said that leaving her husband was not an option, and she wanted them to see their children grow together.

Jimador had therefore much to win by treating his wife nicely, what he also seemed to do, as a contrast to what is often viewed as traditional Mexican male behaviour, which for example Benito in chapter 4 seemed to follow. Jimador chose to act differently, first and foremost because he is a reflected man towards himself and others, and secondly he seemed to be able to do so without the risk of losing his respect as a man, which he won by quite hyper-masculine behaviour as a youth. Later this was

transformed into the role of an engaged and loving family man. He seemed to have lost the “feel for the game.” (Bourdieu & Wacquant, 1992:128). His way of acting, his *habitus* changed, as he grew older²⁷.

His social and economic status, which seems higher than any other of my male friends and informants, does definitely help him, but what I think is more important, though, is his ways of playing his cards; that is social and cultural capital.

Jimador: I would be very happy, if she just would have done it out of love. Because when you love, and when somebody loves you honestly, you don't think about sex. Or at least it comes far behind.

Margarita: Perhaps that sort of love arrives with the children?

Jimador: Yes, it gets more mature with the children, and it returns with the children. Being happy with the children, that is enough. But I would also carry her on my arm, I would take her out, and it wouldn't matter to me covering her with kisses in front of people!

Margarita: Ai, how emotional!

Jimador: It's good, at least: Because of her I am happy that I am me, you see?

Margarita: Yes, and thank you! You have told me that your life has changed, and that you have to confront it with more sweetness, is that right?

Jimador: I should confront my life with more sweetness: with more peacefulness, and more concentration. With much tenderness towards myself and towards the ones who surround me. You should be satisfied with what you are. Smile to life, because we can't teach our children to be impatient, to be bitter, or to be repugnant and always choose the aggressive words. That's not the way it should be. We should try to be an example for others! If you become disabled that's one thing. But you can choose to become an example, like a mirror to show to the others. So that everyone in society see you, and give you credit.

Margarita: Yes, and they get aware.

Jimador: Yes, and they get aware of how life is. When one is active and then from one moment to the other see the other side: some times I feel that is why God give us our punishments. So we can see, perhaps so we can react, and really value the world we live in, and be an example for the others. For the little ones who go over the limit, so that they can feel the moral a little bit. And what happens when someone see you in a wheelchair? With a disability? They try to look at you with interest, but how foolish they are! Because they don't know my life, and they don't know how this is!

Jimador saw that one as disabled is being observed more exhaustively than other persons. Thus a disabled person becomes a mirror for all the others, a support, so that they, the “normals”, more easily think and reflect upon other's lives, as well as their own. Jimador's reflections are again mirrored in Tanya Titchkosky's *Disability, Self, and Society* (2003), where she argues that “disability is not one more thing to be studied; it is a place from which we can study the meaning of our world and its people (Titchkosky, 2003:237).” She claims that disability is a *teacher*, from which I understand that it is a special location with

²⁷ If his change, which can be perceived as development or maturation, serves as example for other persons in his society, motivating further change, this can influence structure, which again influences agency (Berger and Luckmann 1966).

special “lences” that facilitates, among other things; reflexivity. This is also what I understand Jimador to argue; stressing the important role of people with disabilities in the lives of non-disabled people, as moral guidelines and reminders.

In 2005, I was informed that Jimador and his family had moved to Puerto Secreto, where they had bought a farm which they run as a tourist hostel, while cultivating fruit and vegetables on the side.

Zacharias – the entrepreneur

We chat as we cross the street from Zacharias’ outlet to a fruit bar across the street. “Don’t walk so slowly,” Zacharias says; “time is gold!” “All right; as you say!” I answer, and we both laugh.

Margarita: Is that what you are experiencing now? Now that you have got your own business, your family, and so on?

Zacharias: Well...

Margarita: That time is gold, I mean.

Zacharias: Oh, yes; time is gold! That is true. Well, not too much either, today there is no rush, because it is Friday. Then there is some extra time, you see? I can return home a bit later.

I want to use Zacharias’ story to show how his small strategic choices and shifts all the way back from childhood has provided him with the kind of life he envisaged. Zacharias has polio sequels affecting one of his legs, though he is able to walk short distances only supported by his leg braces. For longer distances he uses crutches or a wheelchair.

I soon got to know Zacharias during fieldwork. At that time he was employed in the first internet bar in Aguatepec, so I saw him regularly when I went to communicate with the outer world via internet. Zacharias had come to Aguatepec as a young boy, when he was about 8 years old. He came for physical rehabilitation, a process that had taken him about two years, and afterwards he decided to stay at the centre, as many children did at the time. Now Zacharias was 22 years old, married, and he had two young children.

Zacharias seemed always to be smiling and laughing, but he was also a hard worker, I learnt. The opening paragraph, which was recorded during my second fieldwork, in 2005, illustrates that he is working to achieve things in life, but also that he is somewhat flexible regarding routines. He is a reflected young man, and it seems as he has sucked in everything that he has learned from life and from school,

and perhaps most of all from Palapa Papaya. He is using his insights to analyse his own life, embodying Anthony Giddens' of our time (Sweetman, 2003).

Since last time we met, he has gone from being employed in an internet-bar, to put up one himself, together with an Italian Signore who has settled in the village. Three years ago they put up their business in common, and it is working well, Zacharias says, when I meet him for an interview in November 2005.

Initially Zacharias got to know about Palapa Papaya, then orphanage and resident school, by pure coincidence. He was in his third grade of primary school in his own village, and he was just visiting Comintla to arrange something concerning his birth certificate, when he bumped into the centre's general coordinator Teresa, and Rita, a nurse and permanent employee from the staff. They told him about the centre, and invited him to come to get professional attention and rehabilitation.

When he returned home he was thrilled, and he told his parents about the encounter, that he had met these people who had invited him to come to a school, where he would get attention, and not least; they had told him that he could learn to walk. His parents reacted with suspicion, because "they mistrusted a lot", Zacharias says. They told him he could not go there, and he should not trust those people: "They will bring you to who-knows-where, or they will let you off at sea". However, Zacharias was himself eager to go, and dreamt about being able to walk, as he, like many polio survivors, was confined to move around by crawling. He opposed his parents and said: "Even if you don't want to, I will go, because I want to walk." "And I want to do other things, I want to be independent." Then, a month or so after the encounter in Comintla, the nurse Rita, who is from the region, came to his house to bring him with her, and in effect she did.

Arriving at Palapa Papaya, the rehabilitation training started with physical therapy, and after just a week or two, Zacharias recalls, he was brought to the hospital in Oaxaca, where he got his legs straightened out through an operation. On beforehand they had taken measures for his leg braces, and when he came back to Palapa Papaya his braces and crutches were awaiting him. However, he still got his legs wrapped up in a plaster cast and had to stay in a wheelchair. When he went back to Oaxaca to take off his plaster and then returned to Palapa, he immediately put on his braces: "With the pain I felt, you know, but I put them on, and started to make my first steps!"

First he was exercising with a walker; "I was walking to the kitchen and back to my room, and it worked!" "With a lot of efforts, that is, and emotion, because I had always had that goal, you know." "To walk, and to be independent." "Well, actually *to be me*," Zacharias says, "and thank God now I am fine."

Zacharias completed primary school in Aguatepec, and went through secondary in the neighbouring village Puerto Santo. Then he went to Oaxaca to study high school. He wanted to go on to study at the university, but he couldn't, because his girlfriend in Aguatepec got pregnant and had their first baby. Thus he returned to Aguatepec to settle and work. Nowadays, with his work in his own internet bar, and a computer course, he feels that he has a good deal of knowledge of that field. Though he never stops learning, he says, and he likes that.

Now he has lived by far the most of his life in Aguatepec, and he feels that he comes from this place now. "Actually I have never really gone back to my native village," he admits. He can not really explain why, he just hasn't felt like it, he says. "I guess I probably have some bad memories from there, that I don't even remember." "But I do remember life was hard there, physically, because I was not able to move around much then."

Zacharias: From the time I understood I was dependent on others always, I did not like it, and I compared myself to the other children. The feeling of always being dependent on my parents or my friends was unpleasant, as I could not walk, and I had to crawl, or others had to carry me. My feet were much crumpled (he shows me how they were fixed in one position). Dyslocation of the bones, it is called.

Everything in life is very difficult like that. I always tried my best, but also the lack of economic resources affects one, you know. My family had very little money in that time. It was not sufficient to pay a doctor, for example, and less a specialist, some orthopaedist, or someone who could care (for me).

He makes clear that his life was hard in the village, linking this to his family's lack of economic resources, which impeded them from giving him the medical supervision that he needed. Worst of all, however, was the feeling of always being dependant on others.

Margarita: How many brothers and sisters do you have?

Zacharias: I have only one sister and two brothers, in total we are four, but I am the oldest one. I was the only one who got polio, due to the lack of a vaccine. My parents lived in a very isolated place at that time, as small peasants, and there were no information about those things. Or at least they didn't know it, that the vaccines are so necessary. Nowadays these vaccines are given to the newborn babies, as it is very necessary; the vaccine.

So my setback was caused by the lack of information on behalf of my parents. I was about two years old when it happened, and I don't remember it very well. But I was walking, and everything, because that is what my parents have told me. I was right in that age, like one of my own children now, or like yours. But then the disease set me back, and I stopped walking.

Zacharias reflects upon his own life, and he is quick to give rational explanations for how things came about. He does not blame his parents overtly for not protecting him against the polio infection, as does none of the polio survivors that I have met. He, as many others, blames ignorance, and explains that the

parents could not have known better. Though; with his choice of not going back to his village, I imagine that he is subtly criticising his parent's passivity, without literally arguing.

Zacharias: My parents did not agree very much in my decision of going to Palapa Papaya, because they had another way of thinking: They told me they did not recommend it; who could know what this centre really was about? Perhaps they stole children?

He explains that his parents had a different sort of mentality from what he had. Plausibly his parents mentality can be seen as part of an "Image of Limited Goods", which Foster (1965) saw as pervasive in peasant societies. It seems quite remarkable that Zacharias, as a young child, was able to convince his parents to give him the chance to leave his home to try to attain his dream of walking, a discussion which the centre's courier nurse Rita probably helped him win, providing the parents with successful stories of other children. It is also possible that his parents weighted their concerns about their son's security and survival with the deprived conditions they were able to offer him, and then considered that they had little to lose. Seem in light of the model which "the Image of Limited Goods" provides, his parents liberated their own work forces, and emotional effort, which they could spend on other persons (children) instead.

Zacharias: Even though I was very young, some 8 or 9 years old, I always reflected, I always had another mentality. I had the mentality to walk, and to be somebody in life, to form a family, and get a job, or something like that, do you understand?

Mentality to walk seems to be important to all of my male friends and informants, who have got either polio sequels, or are paralysed after accidents.

Zacharias: And it was with this mentality I grew up, and I made myself independent from my family very, very early. I started to travel, to Oaxaca, and to Mexico City, and I never really return to my village, where my parents lived.

I started to live permanently in Palapa Papaya. And it was a rational choice I made, because at Palapa Papaya I received all the necessary attention related to my rehabilitation, and it was through this, plus a lot of personal effort, that I could come well out of it.

You know the process of rehabilitation is long, and it is not so easy to bear. It is painful. The surgeries and the operations, ouch: you have to be strong, you know, to stand the pain.

Zacharias: But now I feel very satisfied with everything in life, with my family, with my work, and each day I am striving hard. Everything is all right, now, especially thanks to my family: all in all I am a different person now. From now on, because I don't need to depend on anyone anymore, I can move around by myself. I go wherever I want to go, and I don't need nobody, or nearly nobody, to move around. I can do anything.

Then to be this way, that is a great difference to me, you see. Because it is totally different, that is the point.

Zacharias seemed to be a guy who always got friends, and as he grew up with his disability, he was forced to accept it, though he willingly admitted that life was extremely difficult for him while living with his birth family. One thing was that he did not have access to any sort of equipment that could make his moving around any easier. His parents helped him a lot, as did his friends, but it was the *feeling* of being dependent on others that he wanted to get rid of. Now he seems utterly relieved and expresses satisfaction with his current situation, where he feels independent physically and economically. Prior to that he had made himself socially independent on his birth family, and in exchange he has created strong bonds to his new family, that is his wife and children, and he expresses thankfulness and loyalty to the rehabilitation centre where he practically came of age.

Rejection and support

Margarita: Do you have any contact with your family in the village now?

Zacharias: Yes, I have contact with my family, but, let's say there were some problems earlier, primarily with my mum. Well, I like to be realistic: there was a little bit of rejection. It was just like my mum did not like me, really. I don't understand her reasons. Though, my dad always supported me, and he always showed me more...love. To the contrary from my mum's part, I always felt a bit of rejection.

I saw it, that there was a rejection. It could be because I was like that, all dependant, or that she did not really care, or that she thought that I would never become anybody in life. That I always would be the way I was.

One thing that also comes to your mind when you are a person with a disability is discrimination. And it is worse if it is within the family, or perhaps it's even worse if it is from your friends, I don't know.

Despite of his blatant success, Zacharias admits that he felt discrimination inside his own family, from his mother, who he felt did not accept him. He saw that there was a rejection on her part, he says, and he suspects she did not believe that he could become anybody in life. I think that her detached manner might have made him extra eager to fight for his own well-being.

The reaction of Zacharias' mother also seems to echo Nancy Sheper-Hughes' *Death Without Weeping* (1992). Sheper-Hughes understands structural poverty as the underlying root of some mothers' seeming indifference to child death. Certain childhood diseases were also seen as stigmatising, and it was thus understood that the mothers were afraid that their child would end up invalidated, understood as weak and forever dependent if they were to survive alleged non personal childhood diseases.

Perhaps Zacharias' mother unconsciously had expected him not to live up, and therefore she would not create deep attachment to him as a child.

I can not know the mother's motives for not loving him, or his reasons for feeling that way. Zacharias acknowledged that both his mother and father had helped him a lot practically, for example in carrying

him to school and back. As a peasant and mother Zacharias' mum also had to care for his three younger siblings, in addition to working on the fields, and perhaps just did not have the extra energy for caring emotionally for a disabled child. This fits Foster's idea of "Limited Goods", where he claims that also "friendship, love, and affection are seen as strictly limited in peasant society..." "Widespread peasant definitions of sibling rivalry suggest that a mother's ability to love her children is viewed as limited by the amount of love she possesses." (Foster, 1965:298)

She did certainly not conform to the ideal of the suffering and self-sacrificing mother, which is the main ideal and image for Mexican women, epitomized in the national saint, the Virgin of Guadalupe. What is significant, though, is that Zacharias' father did show him love and affection, and as a grown up Zacharias seems to try to live up to this model of a good father. Although his wife primarily cares for their children during the day, Zacharias also takes pride in doing house duties and care for and play with their children.

Margarita: How are you as a person?

Zacharias: As a person, well, I'm very positive, and with a lot of perseverance, that is: I always think about the future.

That is because of my family. I always want the best for them, for myself and for my family. I also like to be patient, but most of all, definitively: to be positive. That is the only way that works to reach your goals. That is my characteristic, I think, that is how I identify myself: as a very positive person.

Zacharias seems to be acutely optimistic, but he is also quite realistic, something that works out as a good combination. Above all he is a hard worker, and adding patience, he have been able to reach his goals so far.

Having explicit goals is not very common in this environment, and having them and working against them, one risk being labelled "ambitious". Ambition is, as I described in the previous chapter, not seen as a purely positive feature.

Margarita: What do you think have influenced you to be the person you are?

Zacharias: It might be the conduct, and it might be that I always had my own mentality, I always had objectives, and I always had plans for the future. I always thought about the future, never the present.

I made priorities: and first of all it was studying. To study was always on my mind, and in deed I was studying, also while I lived in my village. No matter that I didn't walk, but with my parents' support, which I really appreciate now, they carried me to school. My parents also had to work both of them in order for the family to eat and survive. Then they had to make a double effort in bringing me to school and back, so I see now that the situation was very complicated for them, but as I was not able to move around by myself, they had to do everything for me. They even had to wash me, but I was also little.

In school I was always a good student, until I reached high school. Until then I always enjoyed school and everything about it.

I think what has made me become something in this life, and have a family and things, is thanks to my way of thinking. Always putting up a goal, and saying that I want to do things, and try to make it come true. That could be the reason, or at least it helps a lot.

Margarita: There are many things that might influence the development of our personality...

Zacharias: Yes, that is also true. When I came to Palapa Papaya, I felt that I always had someone to rely on. There was always someone to talk to. To be true, that is where I received most of my formation, because I did not get anything like that at home. Well, I was young, but I strongly feel that in Palapa Papaya I was taking shape: through the attention, the education, and everything else that I acquired at the centre. There were courses and orientations, about self sufficiency, and about how to surmount oneself, and a lot of things like that. That also makes you think, and gives you another mentality. It makes you think about what you really want to do with your life.

The fact that Zacharias first could establish himself as a person inside the rehabilitation centre Palapa Papaya, and later move on to the village and the world outside have eased his identity shaping. He did not experience the different types of pressure towards his person as the ones who come from Aguatepec, or are established here prior to their affiliation to the centre. They might experience pressures and expectations from their families, the village, as well as from their own history, which might not harmonise well with the expectations from the centre. In Palapa personal ambitions are welcomed, though communality is also implemented, both in the centre's policy and practises.

Margarita: Do you have any heroes?

Zacharias: That can be a lot of things..., but yes, I admire many persons, like in sports, for wheelchairs: I admire my friends, because I have some friends who are professional sportsmen, who earlier were just like me. I know that with a lot of effort, things will work out. If you only put up your own proposals, then what you really want will come true, what you dream about.

So, during some time I was also playing basketball actively, while I lived in Oaxaca. We had a group there, playing basketball, and we even made it to the national finals, but actually I don't think that was right my field. It might be that my field was another thing, because I feel that I did not really adapt. I enjoyed it a lot, but I could not have put in another gear. That is the truth, but I do admire my companions, who in a way started out just as I did, and like me they are people who make a statement day by day.

Zacharias had the opportunity to engage actively in sports, while he was studying in the state capital Oaxaca, something he appreciates, but as the realist he is, he also evaluates himself as not talented enough to go on with that on a higher level. The example set by other disabled sportsmen is nonetheless something that seems to further motivate him to achieve his own goals. In November 2005 Zacharias was part of the winning team in the triathlon competition arranged by the centre. (He was the first to reach the goal, receiving a full shower of confetti, as the other participants did,

as well.) He ran a distance of approximately 5 kilometres of which the first part was a steep downhill, in his wheelchair which was properly fixed the last night before the race.

Sports

Margarita: Wait a minute: you are the winner of the triathlon. Congratulations!

Zacharias: Thanks. You know two years ago, I came in last.

The team I had formed then did not make it, because of the swimmer, who came in very late, so when it was my turn, everybody arrived but my runner, he came in last, and I was not able to recuperate the loss, so I was the last one to reach the goal!

This time I did not know about the competition until three days in advance. Then somebody came to advise me, and I was invited to join the group that won. Also my wheelchair was in bad shape, and I had to work on it, just like Timo, I think. There was just enough time to make it, and I was lucky, because I joined a very strong group. And also my abilities in the wheelchair helped us, so we could win over all our rivals! And it was a very good event.

Margarita: Yes, a lot of fun.

Zacharias: Yes, it was really a lot of fun. You know I arrived, and took off, and I had an advantage of nearly two minutes, more or less, to the one who came in second. And I didn't even force myself much, only a little bit, most of all it was like relaxing my muscles. That was good, because I had not been wheeling lately, as my chair was mangled. Therefore I was always moving around on crutches. When I am working I hardly need them, because I am sitting most of the time: that is when you start to produce more fat, also, and your heart gets more work to do, especially within a competition. But it was good, and I think that next years' event will be even better.

The leaders of the rehabilitation centre are also vocal about sports: it is not only something that they welcome, but they also encourage participation and interest. A commentary from Cantinflas, current coordinator for the area of rehabilitation, as leader of the weekly assembly at Palapa Papaya preceding the competition, illustrates this: "Now, at this meeting, and in these days, there have been so much talk about sports: this is what we earlier wanted and longed for at Palapa Papaya, and now, finally it is becoming reality!"

Zacharias: By the way, someone in Palapa Papaya mentioned that there would come a person from Sweden to make a reunion with persons with disabilities from Palapa, to talk about a sponsorship, I think. We might get a sponsor for wheelchairs, so we can form a basketball team. This is interesting, as there are several people who want to do sports, I think, and it is only the equipment that is lacking.

I told people from the centre that I want an invitation to that reunion, because I want to participate, for sure.

Margarita: What do you think of sports in the life of people with disabilities?

Zacharias: Well, it depends on what sport, but actually what is most important is that every sport has a certain discipline. In practising sports you have to engage a 100%, of your time, to be a good athlete.

So you need to practise a lot: I know, because earlier, while I lived in the state capital Oaxaca, I dedicated a lot of time to sports, as I really liked it. I didn't have any responsibility but myself at the time.

Margarita: Did you receive any special support?

Zacharias: No, but I knew what I had to do, and I spent a lot of time exercising.

I went to the gymnasium, I went swimming, I went to the pool, I went wheeling about three times a week, around 10 kilometres, and I played basketball every day, in the afternoon, in a special Sports Unit for persons with disabilities in Oaxaca. Yes, we always met in *el DIF*²⁸, and there I had a special wheelchair for playing basketball, and one for racing as well, so I had everything I needed. What is needed to practise sports, that is, because if you don't have what is needed, you can't enter the discipline! You need equipment. It might be that you really want to do sports, but if you don't have equipment, you can't practise.

So it is really a question of engaging, to start forming a group. A basketball team, or another team, because this can really be something for the future! It depends on the eagerness you have got. You might be able to achieve records, perhaps on a national level. You might end up playing against teams from other states, and everything! But you need to have discipline.

Zacharias emphasised the need for proper equipment and facilities, combined with personal engagement. Here he meant engagement both on an individual level: in the sport discipline one practises, and at socio-political level. Everybody with the same interests must join forces to make a strong pressure on possible sponsors. Zacharias saw this organising as means for reaching that goal, however, not until he could almost touch the goal he applied himself, by requiring an invitation to the meeting where the actual sponsor would be present.

Half a year later, they had been able to form a basketball team, with the help of the Swedish sponsor group.

Friends and the struggle against discrimination

A Mexican proverb says "friends are life's angels": *Los amigos son los angeles de la vida*. Friendship is a highly treasured human relationship, which the institution of *compadrazgo*²⁹ perhaps most strikingly demonstrates.

²⁸ El DIF (Integral Family Development) is a public social service organisation that embraces several sub-organisations meant to assist the country's most vulnerable population, especially children, but also people with disabilities. There are DIF offices and different sorts of facilities in all Mexican state capitals, as well as in many municipalities, though not in my fieldwork areas.

²⁹ The *compadrazgo* has been an important topic of ethnographic research, as the "first distinctive aspect of Latin American social structure to be discovered by anthropologists" (Foster 1969:263)

The *compadrazgo* in Latin America is a system of ritualized personal relations established between three sets of individuals: the child (*ahijado*), his or her godparents (*padrinos*) and the parents, who are from now on *compadres*. Here, the latter ties take precedence over those between child and godparents.

Zacharias: As a person with a physical limitation, one always has to fight against that (discrimination). It's an obstacle that you should never let turn you down, because it is just psychological, you know. If you believe in it, and you always think about rejection, that people look at you, you have got a problem. People will look at you, but not necessarily in a malevolent way. I always tried to ignore that, right from the start.

Because I had friends, and my friends supported me a 100 %. They helped me, helped me move around, or anything, you see?

Margarita: Yes, I see. Was that here in Aguatepec?

Zacharias: No, it was in my village, but also in Aguatepec! When I was in school in Oaxaca I was able to walk with crutches, and I always had super friends. Having friends helps you so much to be the normal person that you are. Here, (pointing to his head), we are up to a 100 %, we might even be better than another person, who walks, you know.

So it is only a way of looking, it is just a physical limitation, right? That is: you can't carry things, you can't bring heavy things, there are certain things that you can not do, but everything is working fine in your head, you know. You don't necessarily have to carry things in order to be somebody in life, there is no such rule.

Zacharias is content with his life in Aguatepec. The early independence he established from his birth family is something that he has exploited positively. He seemed not to be experiencing the same strong dilemmas that the persons who come from, or are established in Aguatepec prior to their engagement with the centre do, as he is not feeling the crossed pressure between his family's position in the village and the centre.

Visions

Margarita: Do you feel that there is equilibrium between your own forces and expectations for your life, and what others think?

Zacharias: Well, I feel there is a balance. I feel that everything has been running smoothly until now. My family is what really motivates me to achieve things in life. To think, and create projects. I have got a lot of ideas about things I can do, and I think that I can reach everything with an extra effort. I always put up goals, or what I want to do in life, and although I feel that everything is going fine, there is room for more. You can reach everything you want, if you keep strong and positive.

Margarita: What vision have you got for the future for persons with disabilities?

The *compadrazgo* is usually associated with life-cycle rites within the Catholic Church, especially those of baptism, confirmation, first communion, and marriage, although *compadrazgo* ties are also established at other occasions, such as school graduation.

Ideally, *compadrazgo* ties are highly formal, consecrated by use of *compadre* or *comadre* (for females) as the mandatory form of address (regardless of pre-existing kinship or friendship ties), and the use of the formal *Usted* rather than the informal *tú*. In actual behavior, *compadres* may vary widely from the ideal model, so that different degrees of informality may exist between sets of *compadres* according to the degree of daily social contact, kinship ties, socioeconomic status, and other variables. It is normal to call a close friend *compadre* or *comadre*, as a way of showing that this is really someone you appreciate.

Zacharias: First you have to remember that no one is excepted from this reality. You can be sane today: today you can walk, but no one knows what will be the reality tomorrow, an accident can always happen, and that can leave you disabled. Then it is important to see that that is not the end.

There are always ways to go on. If you are physically disabled, there are ways of thinking, ways of being strong, so that you can fight, against everything. The barriers can be overcome: you can go step by step, like I did. From the ground, and little by little, I was climbing, no: I was destroying those obstacles that put limits to my acting.

However, one needs to make proposals, because life does not stop. Life continues, and you must always use your powers and desires to live. So, I think everything is possible, and the message is that even though having a disability might be very complicated, because one has to fight against everything, society included, the solution is to go on fighting!

In Zacharias' way of arguing I hear the resonance of the centre. Here Zacharias was embodying the centre's line of fighting against discrimination. The fact that his wife has also partially grown up at the centre, where her mother worked in the kitchen, might be a reason why he seems to be utterly positive to the centre. Through this influence they have incorporated some shared values, experiences and knowledge, and they have built up much shared social and cultural capital. Both come from out-of-town, and therefore they must not feel the conflicting pressures that some people who are settled in the village prior to engaging with the centre seem to experience.

Also, there is a notable difference between people's perceptions and attitudes towards disability in Aguatepec and in other villages. "In the villages you can hardly see that people have children with disabilities," Zacharias said. "It makes them ashamed to take them out and walk on the streets with them." This is something all of my friends and informants in Aguatepec have reported, though some through referring to their own shame and fear, phenomena which are fundamentally interlinked.

Happiness

Margarita: What do you think is most important for your own happiness?

Zacharias: The most important thing, hmmm... To be happy: well it is always important to have a good health, and to have a job, or to keep on studying, or like me to always be reading a lot. I am always searching for information. And it is important never to depreciate time, because as we agreed earlier: time is gold!

Time is life, you know. Then we must always make the best out of it, and always engage in something, I believe. There are a lot of things left to do: a lot of things to see, a lot of things to explore, and so on. I am always doing things, if I'm not at work, I am at home, doing my housework, cleaning and stuff. As it is my daily responsibility.

Zacharias: Last weekend I met some old friends. We used to study primary school together, and now we hadn't seen each other for nearly 20 years. They were the ones who recognised me, as I really did not remember them. We were only kids by the time we knew each other, and the face changes over the years, you know.

It was probably easier for them to recognise me also, because of the crutches, and I heard one of them say to the other: "that is Zacharias". I was just going to order something to eat; I was together with my family. But I turned around and said "oh, my name", and I said "hello", and they said "whoa; is it really you?" and I asked them if we knew each other. "Yes", one of the two men said. I said it might be that the other ones knew me, but to be true I was not able to remember them. They told me we studied primary school together, and that we were in the same group. "We have always remembered you," the man said, "but we have never come to this village before. And now, what has happened in your life?" "You seem very different now," they claimed.

Well, I introduced them to my family, and my children, and everything, and they were very much surprised.

Zacharias: So many years have passed now, and I tell you, it is all a story.

It is a story that I actually feel I need to write down in details. Point for point, how everything came about. The evolution: Everything is important in this life, you know.

As a person Zacharias seems exceptionally optimistic about everything that he does, and he seems conscious about his own position as a local role model. I remember from my time as a volunteer in Palapa, Zacharias would always come out from his work to greet us and joke with the young patients when we passed his workplace on our way to the beach or to the village. Now that he has got his own business, many persons from the rehabilitation centre, both patients and workers, prefer his place for doing e-communication and computer work.

Abraham: I don't mind washing clothes

Abraham's story shows some of the variances in men's life strategies.

Abraham was a young man with polio sequels. He came from a community near the town of Puerto Secreto, so he had gone "from port to port", he commented.

Now he worked permanently at Palapa Papaya, as coordinator of the garden area. This is a vital part of the centre, and the local conditions for cultivation are excellent. Abraham is married to Irma, who is also a polio survivor. She works in the kitchen area of the centre. Together they have two kids.

From what Abraham had told me earlier, I understood that he had a relatively safe and protected childhood. He grew up in a small community in a family of 10, which was not an uncommon size for a family. He was the youngest of three brothers and he had three older sisters and two younger ones. When he was 6 he got polio, as the only one in the family.

Abraham: Well, I have been told that I couldn't walk any more, because I was sick. I got a lot of fever, and after the fever I was left without much force from the waist and down, practically immobile. Thus afterwards I was just in bed, in bed. I couldn't even sit any more, because poop: I fell!

Margarita: Did you know what was wrong?

Abraham: No, not until later when my dad brought me to Oaxaca to see other doctors. They said it was polio, and that I had to stay like that always. I would surely not be able to walk any more, they said, though they did want to operate on me, but I didn't want to.

They wanted to operate on me to see, and to make studies.

Well they wanted to bring me to the City of Mexico, and they wanted my dad to sign a paper, so that they would not be held responsible for my returning dead or alive, so that they should not have any problems if something went wrong.

That was their idea, but my dad said: "No, if he is going to die, it is better that he dies at home, that's how I look at it".

Abraham explained his father's action as supportive and caring. He was around 7 years old when his father opposed the doctors' proposal.

Margarita: And how old are you now?

Abraham: I'm 30, no 31. I'm getting old now, really, but thanks to my dad. If my dad had firmed that letter, they would have brought me to Mexico, and there Abraham would have ended, don't you think?

Margarita: Sssssss (scary). But later you have had that operation, haven't you?

Abraham: No, what happened is that later they got to know a doctor who worked in the Marine, here in Puerto Santo, and he was a very good doctor. He told my dad to bring me down to the beach, and that he should bury me like this: half of the body under the sand. First it was for half an hour, and later one hour, two hours. And the sand had to be very hot, and this should help my blood circulate. Thus my dad always did that to me. He brought us (me and some of my siblings) to the beach, to bury me for a while, from the waist and down.

Another thing the doctor told him was that I should swim a lot, and as there is a river close to our house, I would stay there swimming all day. I think that helped me a lot.

Abraham's father's decision of not sending his son to the capital for an operation can be seen as an expression of the same sort of scepticism which had made Zacharias' parents try to prohibit their son attend Palapa Papaya. In Abraham's case the doctors also expressed the risks the operation they wanted to perform could represent. While Zacharias explained his parent's view as backwards, and as a result of their traditional mentality, Abraham sees his father's decision-making as utterly good. While Abraham's father also mistrusted the doctors, he was neither satisfied with status quo. He actively sought other solutions to help his son, and engaged in his son's rehabilitation.

Natural rehabilitation

Abraham: Later I crept. When I was around 8 to 10 years old I started to creep, as I didn't walk, I crept! And then, from I was around 10 – 11, I started to rise up, and stand. My dad had a wooden kitchen, where I could support myself, you see? I clung to the walls and the furniture!

And that's the way it went: I didn't use crutches. Never, I just crept, and then I rose up suddenly, and then I crept again, and like that. I didn't even know about crutches. As there it is really the countryside, you know. There is not much connection with the rest of the world, with the atmosphere of the city...

Margarita: I see, and when did you start to use the bicycle?

Abraham: The bicycle, I was grown up when I started to use it, but prior to that my dad had bought me a tricycle. I used to ride it with my hands!

With my hands, look: this is how I drove it (*and he demonstrates pedalling in the air*).

Margarita: Cool!

Abraham: As the tricycle has got a sort of base in the back, you know, where the small wheels are?

And there are three wheels, right? So I put my feet here (*on the base*), and I pedalled with my hands, and that's how I got around. And then little by little, I learned to walk, and then I abandoned the tricycle, you know.

Then the bicycle; I learned to use it in my early twenties, and from that day until now, I won't leave it!

Abraham was always smiling and joking, and did not seem to take himself too seriously. He was usually biking around the area, compensating his natural difficulty for walking. He explained proudly how his *natural rehabilitation process* came about. In the process his father was active, encouraging his son to go swimming, and then later got him a tricycle which further helped and challenged the boy. There were a few similar accounts of other fathers taking responsibility for their children's rehabilitation outside an established health system. I think these men exploited the advantage they had of more mobility and spare time than mothers, who were often busy with other children.

Palapa Papaya – circumstantialities – and work

Margarita: How did you get to know about Palapa?

Abraham: That was also because of my dad, as he brought my niece here. Her family wanted her to have an operation, because she had an umbilical hernia.

Here they told my dad that since the girl was almost a baby still, she should better wait until she was 5 or 6 years old. After that they came here like a couple of times, and the last time my dad mentioned he had a son who had got problems with his leg, and if they knew what he could do? Then Teresa said "bring him here, so I can get to know him, won't you?" "I want to meet him!"

I studied in Comintla then, and I met Teresa, and she told me "you should come here!" Thus they gave me like three appointments with her, and after that an orthopaedist came here, and he made me some braces, so I could walk, as I do have feet, you know!

It was also in order to straighten out my leg, but I didn't like the brace. It hurt a lot, and as I was used to not using one, I abandoned it. Well, I used it until it got destroyed, and then afterwards I said to myself: "not any more".

But that is how I met Teresa and the centre. Later I came here to do my social service. I was helping out in the school area. I stayed there for like half a year. After that I stayed as a volunteer for 3 or 4 months. I was also a volunteer!

Yes, it's true, but afterwards I needed money, for some things that one needs once in a while: If you want to go to the beach, you need some money, don't you? For personal things. Then the volunteer who was in charge of the garden at the centre told me: "I will leave now, but I don't want to abandon the garden. We need someone who is in charge!" Teresa had said "well, we have got Abraham, let's see if he wants the gig!"

Teresa told me to choose the area that I wanted, but I said "look, if you want, we try the garden, and I will stay for some time, to see if I like it." "If I like it, I will stay, and if I don't: I'll quit!"

She said; "great, come on!" and that's where I have stayed, until this day. They haven't fired me from the garden yet!

So, also for Abraham, getting in touch with the rehabilitation centre was a matter of chance, or circumstantialities. Once he had established a contact within the centre, with the *mera-mera* ("chief of chiefs"), one opportunity followed the other. His social capital, that is, his contacts, networks and acquaintances was essential. That gave him *palanca*³⁰. His father was the *palanca* who enabled access to the influential *palancas* which the centre Palapa Papaya represents, who have persuasive power based on good-will in relation to people in the health sector, and others who are willing to sponsor projects.

Love

Abraham: And later I met Irma here. She had also been a patient, but she was already working when I came. She was working here!

She was working, and then I came, and messed up everything! Yes, I came and stayed for a while, and then I left again. I went to Acapulco to work.

There I was working for almost a year. First as an accountant assistant, and later I worked in an ice-cream shop, counting the money. Afterwards I came back here, and after my mother died, I stayed here for good, as I said: "now I don't have anywhere else to go, this is all that is left for me!"

And that was it, but well, I was already going out with Irma. She was my girlfriend, and she got pregnant, and Marco was born, and well: we made our life together!

We stayed for a year and a half in Palapa, living here. After that we made our own house, and we moved there to live more relaxed. That's how everything came about.

30 *Palanca* literally means 'lever, but is much used figuratively in Mexico and other Latin American countries as a influential personal relationship. In the Mexican linguist Raul Ávila's "DIME – Diccionario Inicial del Español de México" (2003), *palanca* is defined as "a person who has got power or influence to help someone reach something". A *palanca* is beneficial because he or she is able and willing to do you favours. In Spain such a relationship is an 'enchufe', while in Bolivia and possibly other South American countries the term 'muñeca' is employed.

Larissa Adler Lomnitz states that wherever bureaucratic controls play a role in the life of the individual we will find the institution known as pull in the US, 'blat' in Russia, 'cuna' in Chile, 'protetzia' in Israel, *palanca* in Mexico, 'guanchi' in China, and so on.

George Foster's comparison of Catholic Saints with 'palancas' in his treatment of Patron-Client Relationships in Tzintzuntzan (Foster, 1963) is in fact telling, as these are believed to work as beneficial intermediaries ("palancas") between the devout petitioner and God.

Abraham's story about his relationship to Irma was straightforward and uncomplicated. When I later heard her version, it did not appear that easy, which I will return to in the next chapter. Now I want to focus on Abraham's choice of partner in view of his earlier unease in establishing rapport with persons with disability.

Discrimination and support

Margarita: ...didn't you say that you had got some bad experiences related to your disability also?

Abraham: Well: with people. In the beginning it was hard, when I started to go outside our house, because in the village where I lived, I was the only one who had got problems.

There were around 50 people there, and among everybody there was only me who had this disability. My companions at school were always making fun of me, they laughed at me. But my teacher, you know: in order for me to come to school, she carried me on her shoulders! She supported me, she lifted me up on her back, and off we go!

And that's how I could get there. But the worst experience was the mocking from the other kids. What they said: "Look how he's walking!" I didn't use sneakers, or shoes. Nothing, I used to be barefoot. Sometimes all the children went out to play, and they were doing physical activities, and things. Well, I was supporting, nothing more, as I couldn't do all the things that the others did.

And they were always laughing at me. I felt bad, a little bit, do you understand?

Abraham experienced his companions' mocking as very painful, but at the same time he experienced a totally contrary and almost self-sacrificing attitude and practice by his first teacher, who stopped by his house every morning to carry him to school.

Abraham: And little by little as I was surmounting myself, I met new friends, and then finally, I was little by little getting out of my depression.

Though it was not until he grew older and got his own, real friends, that he relaxed, and got out of his depression. For him also, his friends, at some point, became his life's angels.

Overprotection

Abraham: Then the new problem was going to the city, or just going to another village. Going to Comintla, or to Puerto Secreto: That was very difficult for me.

Margarita: Practically or emotionally?

Abraham: It was the emotion part, it wasn't difficult practically, really.

The thing was my parents didn't let me go.

"You can't go alone, because you can't cross the road," they said. "You have to cross quickly, because of the cars: they can run you over!"

My parents always kept me with them, you see. I told them "no, I have to try on my own, because I won't stay under your safeguard always." "I have to step forward, and be independent!" But my dad was always holding me back, he didn't let me be alone. And sometimes that makes you a bit useless, because instead of supporting you, that makes you more isolated. And so on. But thanks to the fact that I kept on studying, I got to see more things, and I thrived in that environment!

Now I can go to Oaxaca, to Mexico City, to wherever it is.

Here in this environment I'm without fear that someone sees me, or laugh at me, or that the cars pass. Now I have got everything more or less calculated!

Here Abraham acknowledges that even though his family was very caring for him, this was not only positive. Their care and protection for their son was also hindering him from moving around freely. As most parents, they were afraid of losing their child, and therefore they did not let him go other places. Overprotection made Abraham more dependent on them, and more isolated. Now finally he feels free, and in charge of his own life.

Disability

"The first set of sympathetic others is of course those who share his stigma." (Goffman, 1963:31)

Margarita: Did you know other persons with disabilities before coming here?

Abraham: Yes, at the school where I studied there were some. But at the same time: I never really knew them, as I never talked to them! Well, it was for the same reason: I didn't feel accepted, by myself. It felt disgusting, I don't know, but I felt really odd if I were to talk with someone who had the same disability as I.

What I did was better, you know: escape a little bit, you see? Look for other friends without disabilities.

It seems like Abraham at that point of his life had incorporated the hegemonic "normals" view on disability to such a degree that he rejected both himself and other persons with disability. Thus he acted just the opposite of what the quotation from Goffman implies, that persons who share the same stigma will become the first *sympathetic others* for each other.

Later in the same book, Goffman says ironically that the stigmatised might become the normals, that is: just as discriminating as the normals, as they tend to adopt the same views and values, and the same understanding of personhood.

Abraham: What I looked for were people without disability, not with. It was not until later that I said to myself: "wasn't I crazy?" I should have shared my experiences with them, in order to support them, if they were depressed!

It seems as Abraham had to learn to accept himself, before he could acknowledge other persons with disability. For others, it might work the other way around: The fact that they respect, and perhaps admire someone with disability, also help them to respect themselves. For Abraham and Irma they both had to come to terms with themselves and learn to accept themselves before they could fall in love, and become each other's first sympathetic other.

Abraham: But I didn't realize until very late, don't you agree?

Margarita: Well yes, but it's not easy, when you are so...

Abraham: Like wounded, or hurt.

Margarita: Perhaps one has got enough with his or her own problems then.

Abraham: That's clear, but I am glad I overcome all that. Now I can support others.

A stigmatised person's incorporation of hegemonic values might be explained psychologically as a result of a weak self-consciousness. It is therefore a pattern that might be unlearned, or one might "grow out of it". *Unlearning* might happen more or less consciously as a result of one's experiences, or as a conscious course of action with one's own fear and prejudices. For Abraham it seemed as the encounter with Palapa Papaya, where they had specific awareness towards discrimination, was decisive for his unlearning. Now he regretted his former reluctance to hang out with other students with disabilities at school: They should have supported each other!

Abraham: Here in Aguatepec there are a lot of other people with disability. That has made me feel more free here, I think. But, not now; it was more in the beginning, when I first came here. As I saw many persons with disability here in Palapa, and then you went out in the village, and there you also saw people. I said to myself: I am in my environment!

But not now! Now I can go to any village. Sometimes I have been asked to help those in the CBR projects go visit communities. There people look at you, you know. They keep looking at you, and things, but what the hell. Now I have overcome those things!

Abraham stresses that the change of environment has helped him lose his old fear of people looking at him or talking about him, and about his deviant body. In this respect it seems like Palapa Papaya's influence on the village of Aguatepec have been substantial. It must also be taken into consideration that Aguatepec is not just any village, but quite alternative in itself. Its transformation from being an isolated and sparsely populated spot not even on the map, without communication-facilities, to becoming a quite popular, alternative tourist destiny, with visitors and inhabitants from all over the world, has happened parallel to the development of Palapa Papaya, and it has been influenced by the centre.

In 2005 I did not have the pleasure of working together with Abraham, but we did sit down for a formalised chat.

We met in “la composta”: the new recirculation plant for garbage in Palapa Papaya, which was surprisingly little malodorous. Here they now take care of all the centres’ organic garbage, mainly from the kitchen and garden areas, and they produce a fine organic fertilizer which is used in all agricultural production on the centre’s land. Some of the fertilizer is given away to the nearest fruit and vegetable merchant, who gives them the waste from his store. The rest is sold from their new artisan shop for 15 pesos a kilo.

Earlier Abraham has started a recirculation plant for paper at the centre; and the area is now working almost entirely without his help, by temporal patients and volunteer workers.

Margarita: How do you feel now, as compared to four years ago?

Abraham: I feel fine, because now I can do what I want to do in my work, which is quite perfect!

Nonetheless, the freedom of my work also seems to be provoking some jealous feelings and envy from persons from other work areas here at the centre. Some of them think that we gardeners are not really working, but only letting the time pass by, walking about just for fun! I try to stay optimistic, and therefore I keep on telling my co-worker Tio Beto that “one day they will understand”.

Just as Abraham experienced, and expressively valued his freedom in his work, he also let his wife have a lot of freedom. Lately she had been travelling, to villages and places within the state of Oaxaca, together with the CBR-team from the centre, as well as going to other states, accompanying members of the administration staff, where she had been sharing her experiences as a polio-survivor. Abraham had been staying at home taking full responsibility for their kids on these occasions.

Margarita: How will you describe yourself as a person?

Abraham: It doesn’t matter for me to wash clothes! Sunday is my day. No, I don’t care: I can do any kind of work! In that sense I am not very difficult.

Statements like these are still quite rare to hear in Mexico’s countryside, and it is not usual to see a man washing clothes. Typically women, as mothers, wives or sisters, do this kind of duties. Though, this seems to be starting to change now, and some boys are encouraged to wash their own clothes on their days off from school, just like girls are supposed to do. Though in effect: the mother often ends up doing all the laundry.

Abraham: Also, I feel that I have developed as a person, partly due to the workshops that are held here at the centre, for example in family economy and in human rights.

The workshops, which are part of Palapa Papaya's official policy of enlightening their staff, fit Abraham fine, and I think that these are contributing motivations for his equal-sex-practise, together with his own father's example.

His family life seems to be a "happy-ever-after" story: He and his wife have two beautiful kids who are now approaching their teen ages. The family has just started a small private project, in order to get a new source of income. The pay at the centre is not high, and sometimes it is even missing.

So now they are constructing rooms for rent, and they are already renting out the first one, to Raquel, a young psychologist from the capital Mexico, who is currently employed in Palapa Papaya.

Abraham and his wife share the household duties, and so also the construction work. The children help their parents out to some degree, and they are highly conscious about human and different people's rights. Discourses, practices, and workshops held at the centre seem thus to be given considerations and are brought into play in the family's daily life.

Sports

In the triathlon that just went by, Abraham was one of my competitors. He was running the wheelchair-distance for his team. Earlier I have only seen him bike and walk, occasionally with the help of a stick, but most often he is biking around, to save time. Currently Abraham also is a member of the new basketball group at the centre.

Raul

Raul is a young man who is visually disabled due to a progressive eye malady, though he was not blind, yet. In 2005 he was 31 years old.

His story does not seem to imply hazardous risk-taking, or struggle to capture the youngest, most beautiful women. In contrast Raul was a hard worker, and an engaged young father. He worked in Palapa Papaya, while living in neighbouring Puerto Santo, where he was also born and grew up. He is in charge of the arrangements and care for the special care section.

Since last time he had settled together with a colleague, he had become the father of a little girl, and they were expecting the second one any time.

Well, the affair between the two colleagues, while she was married to another man, did potentially represent risk. His woman used to be married to one of the village's drunkards. However, no offence was

taken by the betrayed husband, who just like *el cuetes*, the murderer mentioned in my previous chapter, had a conflicted relationship with his wife. Raul's woman was thus a great deal older than him, and she had raised children who are about his age.

Raul: I started to work in the Special Care Section four years ago, but in Palapa as a whole I have more than ten years of experience, since 1994. I came here first to ask for help to get to learn Braille. I said to myself that "it's a good investment, as I am losing my sight".

So, Raul got in touch with the centre out of personal interests, after he had learned that he had a progressive visual deficiency. Therefore he wanted to learn Braille, reading and writing in sign language, to prepare for his future. The fact that he grew up in the neighbouring village to the centre made it feasible for him to choose this line of action. If he had lived far from any health facilities, his chances of making steps to improve his future might have been smaller.

Through the rehabilitation centre he received funding for his living expenses during high school, which he paid back through working at the centre in the weekends, and later as a volunteer for two years. Getting connections with the centre seem to be a matter of chance, or circumstantialities, but it is certainly also a question about seeing possibilities, by means of making the most out of one's social capital. This is a generating spiral: by using one's social and cultural capital, one will also enhance it.

Raul: I like working with the youngsters, as my work is with persons with quite severe disabilities, you know, and thus I come to understand and comprehend life a little bit more. I learn to have more patience, and more love in life, because although they have got serious disabilities, they are surviving, and it is to a great extent thanks to their own efforts.

In his reflection Raul stressed that persons with quite severe disabilities survive thanks to their own efforts. That is an important point to make, and I agree with him. Though, for some, own efforts are not enough. They need practical help, with eating, with personal hygiene, and eventually with medication. Persons who are not connected to an institution, be it a rehabilitation centre or other health facilities, are to a high degree subject to their families' care and support. For many this is a good solution, and the only viable one. Though, in such situations the persons might also be object to harsh treatment, and negligence, which again can lead to illness and death. Like Nancy Scheper-Hughes reports from Brazil, and as I heard about on the first day of fieldwork in Laguna³¹, some parents find it better for their child to die from a stigmatising disease, than to end up disabled and forever dependant.

³¹ We spend the first night in Laguna together with our new neighbours and landlords, who lend us the simple two room bamboo-hut where we live. I am curious to learn about the family's history, and I keep on asking. They are "plain" *mestizos*; not *morenos*, that is people with african features, as the majority of the population in the area have. The family come from an inland lagoon; this one is mixed with sea-water. Don Frederico says that tree of the nine children they had, died young. Himself

Sports

Raul was part of the winning team in the triathlon that was arranged in November 2005, together with Aurelio, a blind man from Comintla who ran, and Zacharias, a polio survivor, who wheeled. They formed the only team with disabled participants only, as all others teams had one non-disabled participant. Raul won a grand lead swimming the first distance. (Us other swimmers who were competing on the same distance, came in far behind.)

Raul: Since I was in Primary School I have been running a lot, and when I was in Secondary School I started to participate in competitions. After that I got more motivated for exercising, as I saw that I could participate in more events, and after a while I got in touch with an organisation for blind persons in Oaxaca.

They have a section for blind sportsmen, and the visually weak, and as I am visually weak, I entered this organisation. After a while I started participating in their events. In 2000 I participated in Mexico City, after that in Monterrey and in Colima, bringing back several awards. I have also participated on regional level, as well as in local events here on the coast.

I have always liked sports: swimming, running and football. Earlier, while I could see better, I liked to play football.

It seems that Raul's constant participation in sports has been valuable for his identity formation for several reasons, not least because this has enabled him to focus on other things than his developing disability. It has also given him valuable social recognition, as a boy and as a man.

Margarita: When did you find out that you were going to lose your sight, or at least much of it?

Raul: Well, first I didn't know, it was not until I started Primary School, when I was around 8 years old, I think.

But thanks to the fact that I already knew how to read and write, I managed in school, through asking my companions for help. What they did was dictating what was written on the blackboard, and I could easily copy the notes to my pad. Or the homework, and that's the way I studied. In the text books there were fortunately pretty big letters, and at the time I was able to read those. When I was eight I could easily read letters in broad print from the textbooks, nowadays that is more difficult. But well, at least then I discovered that I could not see well, as I could not read the letters on the blackboard. Though, I didn't know that I was going to lose my sight until later, when I finished Secondary School. Then I got some friends who supported me so that I could go to Mexico City, where I visited the hospital for the blind. Because I went there, and they made special studies of me, and they saw that I had a problem in the retina, a serious damage there. They asked me a lot of questions, and afterwards they told me that this damage would advance little by little.

So I was grown up when I got to know that I would lose my sight. They told me that if the damage had been discovered earlier, they might have been able to delay the progress a bit more, with glasses, or treatments. Now it was too late, it wasn't possible to do anything any more.

he prayed to God that a little daughter who was affected by polio, must rather die than stay *asi*. The girl was 5 or 6, and was paralysed in one arm, so she had to carry it with the other. She died after a while, plus a small girl who had tuberculosis after keeping in touch with an ailing person, and a little boy who was run over by a car.

Getting a progressive and disabling illness is, according to a scientific worldview bad luck; others will say it is destiny, and others again that it is some sort of punishment.

The fact that Raul found some help in his situation was good luck, I will say: If it was not destiny or some sort of reward.

Because he got friends who wanted to help him and who were in a position to do so, he was able to find out what was wrong with his sight and get a valid diagnose. They served as his *palanca*.

My discussion with Garp in the previous chapter, about *los accidentes en los accidentes*, that is, circumstantialities in an accident, depicted the same point.

Circumstantialities influence different sides of a person's living, which again can be seen as shaping a person's personality and feeling of identity.

Here I am not trying to find out what is believed to be the reasons for fortune or misfortune to strike. What I see is that there exist various models of explanation parallel to each others, and that one theory of explanation is not necessarily in opposition to another.

Margarita: How do you feel in life now? I know you have had a lot of changes on the personal level in the last couple of years.

Raul: I feel very good, emotionally, as a person. I am working and doing a lot of things, going high and low, and I don't have the time to be bothered about things, as my visual disability, for example.

And my family is another thing: That is where I find support and understanding. Be it from my wife or my mother. My siblings as well, and all in all: I feel good. I feel satisfied with what I have, as well as my own way of being.

Margarita: How are you as a person?

Raul: Well, I consider myself as an active and hard working person. And kind. I am also very down to earth. I believe that I don't cause anybody any trouble.

And what more? I am affectionate with my family, and with everybody; with the kids with whom I work, and with the volunteers; with everybody. I am quite friendly and cheerful. Also I love music and good food; I am a real eater!

Margarita: Aha, and what has influenced you to be the person you are?

Raul: First of all my mum, I believe. My mother, as I did not grow up with my dad. I never knew my dad, but my mum taught me a lot of things, and I got plenty of love for my mum.

Raul appears simply happy and gracious, content with his own life situation and his personality. He seems like a perfect employee or partner. He grew up in poverty, as son of a single mother, and with seven siblings. His relative success in life seems unlikely, nevertheless it is manifest. Raul's story shows that human lives can not be understood as results of socio-cultural structures alone. Objectively Raul would be categorised as coming from a "broken home", but he has received continuous love and support from his mother and sisters, and has been able to shape his own life to a considerable degree.

Religion as an aspect of identity shaping

Raul: And also, I don't know, but I would also like to mention that I was learning certain things with a religious group, I believe, although I left the group. It is about 9 years since I left the group now. I think it was after I came to Palapa that I left them, but prior to that I had learned a lot of things, about God and about the Universe. Mostly about God, you know.

Margarita: Perhaps that was important in your life or for you as a person?

Raul: Well, I think that it was not so much the religion, but perhaps now it is like seeing the universe, and everything that exists, how we move, the air, why it is raining. All the beautiful things that we have got make me think that we as persons should really care about ourselves, and each other, care about everything that surrounds us. That is what gives me hope: I think we have got a reason for struggling in life.

For everything that surrounds us, for the fact of watching stars in the night, for the universe, and everything about it. The moon and the sun... Everything makes me think that there might exist a superior being that protects us all.

Raul acknowledges and draws on what he has learnt and experienced as member of a religious congregation. However, he has left the group which was former a crucial part of his life, and although he does not adhere to a specific doctrine any more, he still believes in God, and this is part of his current identity. Making sense of life is not just a human (spiritual) need, but a defining property. "To be human *is* to seek sense in life" Robert Segal states in a comparison of Clifford Geertz and Peter Berger. Though, the search for meaning is never fully satiated, Segal points out, because sense is not, like food, found or cultivated, but rather created: to make sense of life is not to discover the way life is, but to organise life a certain way. I would hold that in order to create sense of life, something must be found or cultivated in the first place, and this process also creates meaning in one's life.

For Raul his earlier acceptance of a set of religious doctrines helped him make sense of his life, and he is now able to create meaning in his life also independently of these. It seems as his integration in life and work at the rehabilitation centre in some way took over the place that the religious congregation had formerly occupied in his life-world and mind. For Tito and Garp, who I treated in the previous chapter, the change was the other way around.

Other key elements in Raul's search and creation of meaning have been family and participation in sports, cultural structures that, although their actual content has changed, remain crucial for him.

Disability

Margarita: How has disability influenced your life?

Raul: My life? From what point of view do you ask?

Margarita: Most of all in relation to your own disability, but also related to other people with disabilities.

Raul: Oh, yes, then it is clear. Although I have got a disability myself, the fact of watching other young people, like Sara and Chico, who have got very strong disabilities, makes me see. It makes me stop up and show more respect for life. It makes me look for other options, other solutions.

And to me it is evident that all persons with or without disabilities, deserve respect, we all have our rights and obligations. The fact that you are disabled does not mean that you are more or less worth than any other person. Everybody, as human beings are equal. Everybody has got capacities. Naturally this will depend on your interests, on your wellbeing, on how much you try and struggle. And it depends a lot on your attitude: that you try to look for options.

Raul is a thoroughly reflected person, which is partly resulting from his upbringing, schooling, religious involvement, and his association with Palapa Papaya. He is decidedly convinced that all persons, as human beings, are equal in worth, irrespective of disability, or other differences. Challenged to talk about disability, Raul emphasises that he is learning from working with the youngsters with severe disabilities who are living at the centre. As regards to his own life he is content with small pleasures. He prefers to fulfil the moment, and the present, as compared to dreaming about the future. What he nonetheless hopes is that there will be a better future for people with disabilities in his region. For that reason he holds that it is important for disabled people to work collectively for their interests.

Vision

Raul: I haven't been dreaming so much. Actually it depends also a lot on us. If we are really working hard now, we disabled people, I mean: if we move ourselves now, and work hard, perhaps there could be more improvements for disabled people. More access, more job opportunities for disabled people, because now: if you have a disability you are discriminated. But perhaps later, if you prepare yourself, and study, you might have more opportunities to find work, even though you are a person with disability.

That is what we are looking for. I feel that this is the biggest obstacle for disabled persons now. We have to prepare ourselves, and study, don't you think?

Margarita: Yes, I also think that education is important, and especially for persons with physical disabilities, who are able-bodied intellectually spoken. I believe it is good that these persons study, so they can get a job that is not physical, a job where they use their minds.

Raul: Yes, where they might use machines, like computers and things. So I feel that we definitely need preparation, for the future.

Margarita: And what is the mission of Palapa Papaya?

Raul: The mission of Palapa Papaya... that is to improve the quality of life for the persons... from here around, from the whole region of Oaxaca. That is one mission: to improve the quality of life. Naturally we can not make people who are paralytic walk again now, but we can try to improve the quality of the life that they live. Try to make them happy, see that they eat well, that they have access to other things. That's it: Try to improve the quality of life of disabled persons and their families, because there are a lot of them here, in this region.

Yes, I think that's our mission, if I have not misunderstood!

Raul's story illustrates different aspects related to the search for social recognition. His account highlights the benefits of having a religious conviction when one is faced with challenges linked to disability.

His former engagement with an evangelical group was a valuable step towards broadening his worldview, and gaining self-confidence. His exercise and successful participation in sports awards him respect from his fellows, which dialectically strengthens his self-respect.

The four men treated in this chapter are, as the ones I was focusing on in the previous chapter, receiving social recognition and respect from their environment, in Palapa Papaya and in their hometowns.

However, they are not drawing so much on the aspect of risk-taking. Instead they are employing other strategies, through work, and through intense involvement with Palapa Papaya. They are using sport practice as a means to engage bodily in the world, from what they also receive recognition. They seem well aware of being role-models for other people with disabilities, and embrace this mission. Being fathers and family providers has also influenced their choice of activities and action, and they are employing another end of the machismo scale than violent risk-taking. Their identity and social recognition is dependent on providing well for their families through work and emotional engagement. Their stance towards ambition is differently understood, and they are somewhat ambitious with regard to work.

Chapter VI: Strong Women and Culturally Shaped Strategies

“...our identity is the result of the quality of our suffering”

(Craib 1998:177).

I find this quote revealing enough to repeat it (see chapter 1). In the next two chapters I will namely try to describe women’s strategies for surviving, and living good lives in an environment of poverty and male dominance on the south-pacific coast of Mexico. The women I will portray either have a disability themselves, or they have family members with disability, or they are in other ways closely engaged in the lives of people with disability.

What are local sociocultural ideals for feminine behaviour, action and living, and how do these women relate to these ideals?

In this environment women’s search for recognition in general seems to be very different from most men’s attitudes and practices. For women risk-taking is certainly not a main road to recognition, as it is for men. Women do not gain respect by taking high risks, but rather the contrary: by providing economic and emotional security for their family, and especially for their children.

Women as mothers, sisters, daughters, and wives of persons with disability are often crucial in the lives of their familiars – female and male – and it seems to a high degree to be expected that a woman suffer for her family, and then in particular for her children.

What is guiding these women’s behaviour and way of action?

I will give examples of almost total devotion, as well as the opposite.

In will use the concept of *marianismo*, as an ideal model to explain women’s behaviour here, being critical to what degree the model holds stand.

Marianismo

Marianismo as an analytical concept was developed by Evelyn Stevens as a complementary contrast to machismo in Latin America, where Stevens made her theoretic generalisations with special reference to Mexican society and culture. The concepts of *machismo* and *marianismo* are by Stevens outlined as different sides of the same coin. Machismo, as men’s social superiority over women, is a cultural trait that can be found almost everywhere of the world, forming part of cultural configurations of the patriarchy model, while marianismo is seen as an especially Latin American ideology and ideal of femininity. Stevens defines marianismo as “the cult of feminine spiritual superiority, which teaches that women are semi-divine, morally superior to and spiritually stronger than men” (Stevens 1973:91).

Implied in the marianismo model was originally the idea that a woman should be passive, and that her duty was to work at home, with the upbringing of children, cooking, washing, and etcetera. A man, on the contrary, should work outside of the home to provide economically for the family, and he should be able to guarantee their physical security. Stevens went as far as to say that, in general, women in Latin America will not fight for sexual equality, because they are comfortable with their position here, and that the marianismo ideal provides them with advantages that they want to preserve, such as not “to impose upon themselves some of the onerous tasks traditionally reserved for men.” “They are not yet ready to relinquish their female chauvinism.” (Stevens, 1973:100).

Stevens’ arguments had their empirical base in middle class Mexican women. It is interesting enough that the male model, machismo, seems to be based on lower class society whilst the female model is based on upper and middle class.

Marit Melhuus has nonetheless found much the same pattern in the slightly lower classes. Melhuus found the ideal of men as the only ones taking on paid work to fit her findings neatly, in regards to the population post adolescent, as young unmarried women indeed were encouraged to take on paid work, in the period after they quit school and before they got married.

In her doctoral thesis: *Todos tenemos Madre. Dios tambien.* (1992), Melhuus explains how in her fictive *meztliso* village San Felipe in the Valley of Mexico married women were not expected to take on paid work, as this was seen as setting their husbands honour in doubt, as it then could be implied that the husband-father was not able to provide for his family. The culturally accepted means of getting respect and self-respect for women was instead by the ideal way of passive suffering.

One woman in Melhuus’ account was nevertheless challenging this ideal/norm, by moving back to her mother’s village (San Felipe) with her children, taking up a loan, and starting her own business, while simultaneously engaging herself in local religious and social matters. Her actions were perceived with great suspicion, Melhuus says, by the woman’s fellow female villagers, and it was openly reproached by her ex-husband’s family. What was saving the woman’s respect in her neighbours’ eyes in Melhuus’ account, was the fact that she could be seen as victim of her husband’s abandonment, although she had in fact herself taken the first step by moving away from her husband’s place. This was though explained as a reaction to the husband’s continuous disengagement to family due to his work, which required him to be travelling out of town.

Critique against the concept of marianismo has been centred on the fact that this model of / model for women’s behaviour is too class-based. In other words, this rather sheltered existence, with men doing the hard work, in exchange for the pedestal that women are supposedly on, is a life that rarely exists for the majority of peasant, poor and working class women who make up the majority of the female population in Latin America.

Tracy Ehlers states in her monography *Silent Looms – Women and Production in a Guatemalan Town* that marianismo “is not a characteristic of all Latin American women; it is a result of specific economic and cultural conditions.” (1990:163).

I do agree that marianismo is not an (individual) characteristic of all Latin American women, and in Guatemala the passive pedestal may only be reserved for a very few rich *ladinas*³². However, I will argue that marianismo is present as an ideal, and as an implicit cultural model, in the part of Mexican society that I will try to expose. Though, I do find it necessary to consider the ideal as more flexible than Stevens seemed to imply in 1973.

Stevens’ uncovering of the marianismo ideal is manifest in the veneration of the Virgin of Guadalupe, the most important and powerful cultural symbol in Mexican Society. One can see her image depicted all over society, on postcards and stickers, on banners and t-shirts, and on glasses with a candle inside to glow light upon a dear’s tomb or an altar inside private houses.

While the Virgin of Guadalupe has a unique symbolic position within the people and the nation-state of Mexico, other Virgins and Saints are also venerated. It is recognized that much, if not all, Marian devotion in Mexico follows a “Guadalupan pattern”. Though, “admittedly, the miraculous apparitions of the Virgin, as symbologies filled with efficacy (Velho, 1987, quoted in Barabas, 2000) do not happen in a historical void, but they are part of a global tradition of Marian miracles, which has unfolded in Mexico, creating a specific *Guadalupe* model, identifiable in numerous apparitions of virgins and saints.” (Barabas, 2000:1)

La Virgen de Guadalupe

The Virgin of Guadalupe seems to remain the single most important symbolic image in Mexican Society after the Spanish Conquest. After her alleged apparitions to the indigenous man “Juan Diego” on the mountain of Tepeyac in 1531, the cult to her has just grown. Her image has lead innumerable quantities of people – indigenous, Mexicans, and others – to convert to Catholicism, and her banner has served as the uniting symbol in important Mexican wars, first raised in the liberation from Spain in 1810-1821 by Fray Miguel Hidalgo. Later her image played a part in the Mexican-American war from 1846-1848, with the concluding “Treaties” which bore her name, where peace was firm and the new borders, where Mexico lost about half it’s territory, were drawn. The national heroes Pancho Villa and Emiliano Zapata both marched under the Virgin of Guadalupe’s protective banner when they entered and occupied

³² *Ladino* is the label used for people of mixed ethnic origin in Guatemala, usually they are part indigenous, and part European, and they may have some African ancestry. People of similar descent are labelled *mestizo* in Mexico, and such people have overall different socio-cultural positions in the two countries. In Guatemala they constitute an economically relatively rich minority, whereas in Mexico the vast majority perceive themselves as mestizos and most of them are relatively poor.

Mexico City in 1914, during the Mexican revolution (1910-1921). The current “Zapatistas” who began their regional uprising in the beginning of 1994 also call themselves “Guadalupanos”, and their provisory settlement in the jungle of Chiapas is identified as “Guadalupe Tepeyac”, obviously used for political reasons by the poetic “subcomandante Marcos”.

In 1737 the Virgin of Guadalupe had been proclaimed patroness of Mexico City after being credited with ending a deadly epidemic that ravaged Mexico City in 1736–37, and in 1746 her patronage was accepted by all the territories of New Spain, which included part of present-day California, Arizona, New Mexico, Utah, Colorado, South Carolina and Texas as well as Mexico, Guatemala and El Salvador. In 1754 Pope Benedict XIV approved her election as national patron and he granted her a proper feast and mass for December 12. In 1895 her image was coronated inside her Basilica in Mexico City, in the presence of Catholic Archbishops from all Latin America and Mexican Popular and Cultural Elite. Pope Pius X proclaimed her patroness of all Latin America in 1910, and in 1935 Pius XI approved her patronage over the Philippines. Ultimately, Pope John Paul II proclaimed Our Lady of Guadalupe as patron of the whole American hemisphere in 1999.

By this time, the traditional view was nevertheless being questioned by various scholars and ecclesiastics, including the former abbot of the Basilica of Guadalupe, Guillermo Schulenberg. The primary objection is that there is no documentary evidence for the apparition until 1648; critics claim that documents purporting to be from the 16th century are actually from the 17th. Critics have also noted that the bishop approached by Juan Diego was not consecrated until 1534, three years after the apparitions, and he made no mention of Juan Diego or of the Virgin of Guadalupe in his writings.

In people’s lives the controversy does not seem to have made a big difference. Catholics have defended their *morena*, as well as Juan Diego, who in 2003 was proclaimed a Saint. The claims of falsification probably have made the Protestants more assured that they are right though: that belief in saints are principally wrong.

The devotion to the Virgin of Guadalupe almost makes it plausible to speak about a “Guadelupanismo”, though this is a term which has yet to come into use. Eric Wolf labels her master symbol, since she “seems to enshrine the major hopes and aspirations of an entire society” (1958:35). It is the multivocality of such master symbols that makes them particularly forceful and good common denominators in society, because they appeal to people for different reasons, and they are open for new, creative interpretations.

The image of the Suffering mother, exemplified in the Virgin of Guadalupe, is by many Mexicans seen as their version of the Catholic Virgin Mary, and so also by the official Catholic Church. Others see her as the Aztec Mother goddess Tonantzin: after all her apparition was that of an indigenous girl, who

made her requests in *nahuatl*, the language of the Aztecs. Some see Guadalupe as a figure created for politico-religious reasons by the Spanish clergy of the Catholic Church, others as a symbol of resistance against colonisation. Whereas the Virgin of Guadalupe has a unique symbolic position within the people and the nation-state of Mexico, as I noted previously; other Virgins and Saints are also venerated often following a “Guadalupan pattern”.³³

In the state of Oaxaca the Virgin of Juquila is the most revered religious image. Amongst my friends and informants in Aguatepec, the Virgins of Guadalupe and Juquila were both important.

The Virgin of Juquila is also a dark Virgin, although her colour stems from a fire. In 1633, the small church of the community of Amialtepec, near Juquila village, where the wooden figurine of the Virgin of the Immaculate Conception (about 30 centimetres tall) was placed, burnt to ashes. The statue of the Virgin, which had been given to a native peasant in gratitude of his servitude to Friar Jordan of Catalina, remained intact, clothed and all: just the colour of her “skin” appeared somewhat changed. The statue’s perpetuation was seen as a miracle by the peasants from this and nearby communities and the Municipality of Juquila throughout the years to come became an important pilgrim site.³⁴

³³ It is worth noting that many new apparitions of the Virgin are reported every year to local church authorities, seen in burnmarks in pieces of toast and tortillas, in papayas, in threes, in microwaves, in rock formation, in humidity spots, etcetera. In one of the most famous recent cases is “the Virgin of the Subway” from 1997, when believers saw an image of the Virgin of Guadalupe in a humidity stain in the Metro stop “Hidalgo” in Mexico City. Ivan Martínez, an historic from the Museum of the Guadalupan Basilica in Mexico City, says that the Cathedral receives at least two reports of apparitions a month.

³⁴ Interestingly enough, in late October 1995, till December various “apparitions” and “signs”, which were interpreted as The Virgin of Juquila, were recorded near the river in the village of San Felipe Tejalapam just 15 kilometres from the city of Oaxaca. The first apparition, on October 31, to a young employee of the Conasupo, was that of a young blond girl, dressed in white and wearing new and shining leather sandals. On the night of November 14th, the young man had a new vision on the very same spot; where he now heard voices of young girls calling him. Frightened he hurried to his house, but returned together with his father and grandmother. Arriving at the well, the three of them saw a white veil covering the opening of the well, when they came closer they also saw the crown of the Virgin on the veil, and suddenly “the Virgin was there, wearing her robe and crown”. They knew it was a miracle, because they saw a crown and robe covering the one-metre-diameter well transform into a figure of the Virgin who, with robe and crown, measured 30 cm. On the next day, the visionaries accounted the vision to the local authorities and the parish priest, and it was soon decided to build a sanctuary over the well. Due to the statue’s childlike appearance, her size, and her overall similarity to the Virgin of Juquila, the believers interpreted her as a “daughter” of said Virgin. Very soon the news was spread that the apparition was the “small” Virgin of Juquila who had come to stay in Tejalapam.

In December there was a new and quite different apparition of the Virgin, where the Virgin appeared as a poor child to a traveller. An old man visiting from El Tule found a very dirty girl by the river; her nose full of mucus, who spoke to the man on two occasions. She had three messages: First she healed his knee, (which he had not complained about, though he walked very slowly,) by providing him with water from the well. Then she told him that she lived in the little house by the water, where a provisory sanctuary had been set up to venerate the newly appeared Virgin. Third she gave him a message to the recently formed “Committee”, compound by 40 volunteers who shared tasks related to the Appeared one: “Tell them I will send them lots of water and a very large piece of bread, very special, for all their people.” Afterwards she transformed herself to a vision of the Virgin, then to a Star on the sky, before she at last fell down and disappeared in the well.

Later people in the Committee saw the virgin in dreams, and someone who did not believe in her saw a snake near the well instead, natural phenomena that were interpreted as proof of the Virgin’s authenticity. People from faraway places came to the community to visit the Virgin, and people from the community who had migrated to the city returned to the community, to be close to the Virgin. The local priest was approving of the visions, but the Archbishop of Oaxaca sent an inquisitional Commission who found that the image was a modern and commercial replica of the image in Juquila, which had been found or placed there, but not appeared and, therefore, it was deemed as not authentic.

Suffering

Marianismo is not an indigenous, local, concept, as machismo is, but rather an etic term which is used in Academic work on Latin America.

However, suffering, which can be seen as the epitome of marianismo is indeed an emic expression. The notion of suffering (*sufrimiento*) can be traced in daily local discourse, especially among women, and in the different practices of suffering.

Although the term suffering may have a general connotation of passivity, which is often implied in the notion of femininity in general, in my context I see suffering as an embodied activity (though sometimes passive). For most of my female fiends and informants suffering take the form of struggle, *lucha*, similar to the *luta* that Brazilian women of *Alto do Cruzeiro* describe life to be, according to Scheper-Hughes (1992:9).

The women I will portray in this chapter were suffering, in many ways I would say, though not without laughter. I found suffering evident both in their practice, in their lives and works, as well as in their discourse. Here I focus on suffering as a means to gain social recognition.

What I see as their suffering is their continuous struggling, working and fighting for their families, and then first and foremost their children, and themselves, to live good lives, while managing their own or family member's physical or psychological disability. At Palapa Papaya there were many single mothers (*madres solteras*), who were abandoned (*abandonadas*) by their husbands, and one widow (*viuda*). These women did indeed take on paid work, as a necessity and as a self-chosen strategy. They worked and struggled, and the centre served both as a rescue for them, and as a catalyst for work and activity.

Lancaster's findings from post-revolutionary Nicaragua also show working class women using marianismo as an active strategy (Lancaster, 1992). This does not mean that by displacing the ideal of passivity implied by Stevens, through social action, the marianismo ideal no longer exists. In fact, it seems impossible to eliminate or overthrow the ideal, for, in so many ways, it is ingrained in Latin American ideology and everyday life. Lancaster presents an idea of an active marianismo strategy which still upholds many of the tenants of the marianismo ideal.

The women Lancaster worked with and interviewed rejected marianismo on the grounds that it demands "sexual purity" or virginity. According to the working-class women Lancaster interviewed, this is not an important ideal of Nicaraguan womanhood (ibid. 1992:310). Lancaster thus questions the marianismo/machismo dichotomy: the belief that masculine must be active, while feminine must be passive. For Nicaraguan women, the traditional ideal is not one of passivity, but rather one of "elevated motherhood". "Traditional feminine practice, then, is conceived as a different mode of doing than male practice: feminine action emphasizes planning over risk, self-abnegation over self-promotion, domesticity over worldliness, action in and through networks rather than interpersonal competition." (ibid. 1992:93)

With my female friends and informants in Palapa Papaya neither sexual purity nor passivity was ever a question, as they did not embody these qualities. Rather, through practice they showed themselves to value activity, seen as work, and the work was seen as a self-sacrifice through which they put others (mainly their own children, but also other's children) before themselves. From this, one might hypothesize that although understood and articulated in a variety of ways (as an ideal, a cultural model or – trait, as a passive or an active strategy): the marianismo ideal is still pervasive and difficult to escape also in Latin American working class society.

Dignity and recognition is important for these women, though it is not something they search overtly, or compete for, in the same ways that some men do for respect.

Mari – spirit of mother

During fieldwork I got to know Doña Mari fairly well, as we were interacting every day. She was one of the main cooks in Palapa Papaya and the centre's personified sunlight, always smiling, talking, singing and making jokes. As many other mothers of children with disabilities, she was her family's sole provider, as her husband, and father of her children, had abandoned them. During my first fieldwork Mari was living in a room in the new spacious special care section at the centre, together with her two youngest children: 14-year-old Mateo, and Dinah, who was 12. Mateo had got a progressive neuromuscular disease, which slowly disabled him physically, but intellectually he was very bright. Earlier he had been able to walk and run around, but now he was sitting all crumpled up in his wheelchair. His younger sister was strong and healthy, and had grown much bigger than her little big-brother. Dinah was helping Mateo out with many practical chores, and when she was not at school the two of them were often accompanying their mother Mari in the kitchen. Mateo had recently chosen to quit his school of special education, arguing that he was teased by the other kids there

Their 16 years old brother Eddie was studying in the state capital Oaxaca, where he was living in a house together with other youngsters with and without disabilities, who were attached to Palapa Papaya in different ways.

Mari had also had another son, Felix, who died a couple of years earlier, from the same disease that Mateo suffered. I was told that Felix used to be just as smiling and cheerful as his mother. Mateo on the other hand was quite serious and did not like conversation, other than with his mother and sister. When he talked, it was usually with a sarcastic twist, quite different from his mother. Mari seemed always to be in a good mood: she used to sing to the kitchen radio, and I even saw her dance in between her fellow cooks, whilst no-one else.

Beside, Mari had still one more child, Maria, a grown up girl who used to live and work at the centre as well, but now she had gone to work in another town.

After four months of fieldwork at the centre and in the community, I decided to conduct personal interviews with central persons for my thesis.

On purpose of an interview we entered Mari's room. It was the first time I was inside, as Mari was always to be found working in the common kitchen, a wooden hut in the middle of the centre.

Mari: I am 46, and I have lived the last 14 years at Palapa Papaya. Originally I come from Nisatulco, it's a couple of hours drive from here.

I heard about Palapa Papaya from a *señora*, a neighbour from Aguatepec, who told me about this place, that here they look after children with disabilities. I had got one myself, who is not here anymore, he left. He has got two years now, dead. (*I see her eyes are full of tears.*) Yes, he died, and afterwards the same thing is happening to Mateo.

Margarita: Yes. Destiny can be very tough.

Mari: Yes, with two children with disability: it is harder to look after them. Well. It was harder, but now, as I have got only one, it is almost nothing, more or less, it's good. I'm not relaxing, so to say, because in the nights for example I do get up to help Mateo move around, and to eat, now he almost doesn't eat, and I try to accustom him to eat by himself, you see? With his own hand. Later the same thing will hit me back, as with his brother: he used one hand only, and the other one was just stuck to his body.

Margarita: Yes, I see. What was your other son called?

Mari: Felix (*and she rises to fetch a photo that is adorning the mantelpiece in the middle of the room.*)

Look, here he is!

Margarita: Yes, what a nice photo!

Mari: But here he was more or less, he was moving pretty much.

Felix will turn 23 soon. He was the oldest of my children. They are 5, or they where 5, with Eddie who just come here for a week. Right now he's here, but soon he will go back to Oaxaca. And then there is Maria. Maria was doing training here when you arrived! She was living next to Cantinflas, just behind, that's why she called Cantinflas *vecino* (neighbour). She used to live there by the road to Huachinango, just after the bridge.

Margarita: I see, I only knew Dinah, Eddie and Mateo. But tell me; how was the change from your hometown Nisatulco to here?

Mari: Well, I was born in Nisatulco, but I didn't grow up there. I grew up in a place that they call Toyula. It's a village, just like here. There are festivals, there they celebrate the 20th of December, and the 12th, naturally, they celebrate (*the national saint, the virgin of Guadalupe*).

Margarita: How was it to live there with Felix?

Mari: Well, I never lived there with him. Then I lived in Comintla, for many years I lived in Comintla. And from Comintla I came here. I go wherever they want me to go.

Margarita, laughing: But that's how you are: you adapt to anywhere it seems, because you bring with you so much spirit! Spirit of...

Mari: Of mother?!

Margarita: Spirit of mother, yes, and also something more. But well. Here, in Palapa Papaya, there are more facilities for a child who is in a wheelchair...

Mari: Yes! And here, when they are more or less (*economically*), they help me, you know, with the education for my children, for Dinah and Eddie. They help me with both of them, well, with the three of them, but the last one; she is working for herself now, providing for herself.

Margarita: And what happened with your husband? If there was a husband, that is?

Mari: Yes: It is just like he is dead, isn't it (*laughing*)? I am the mother, and the father, that's me!

Margarita: Yes, that's what I see. But was he frightened, or what happened?

Mari: Well, he didn't want to have any responsibility.

Margarita: But after all the children?

Mari: With the first ones, more or less, with the last ones; nothing. Felix was born healthy, he walked, but later he got affected. Before he got sick he walked, you know. He walked, just like Mateo, now it is like ten years since he stopped walking. All the way till October, Mateo could move pretty much, he sat down on the ground, one could put him down, and he was able to sit by himself, but now it's over: He is losing his control, it seems. It is like he can't hold himself up any more; he has to lay down a lot. In any moment, one has to be very careful with him. And when he goes out, one has to look for him, so that his head does not fall down. Because he is very stubborn, he doesn't want to sit sideward, so that he can relax. He's very rebellious, you know.

You see: he does not lend himself out to anybody, for talking. The other one was not like that: the other one was more talkative, more everything. The only thing that he didn't like was if someone stared at him. Then he was suffering, no, he didn't like that. He got angry, for sure. Yes, he got angry when people stared at him. Anybody stare when they see a disabled one, from top to toe, they keep on looking. They observe how a kid is walking, and they don't know anything! As if they never in their life will have a son or a daughter! They are almost stumbling of surprise, they are left open-mouthed, as if they enjoy staring, at a fellow.

Mari was in a position of defence towards her children, and particularly Mateo, who was very dependent upon her. She was living and breathing for her children, and thus seemed to embody the image of the suffering mother, personified in The Virgins of Guadalupe and of Juquila, though she did not explain this herself. Those virgins are both attributed with healing powers, but their power as models for womanhood and motherhood is drawn from their virtue of suffering (Melhuus, 1992:160), exemplified by the suffering Virgin Mary endured for her son Jesus.

The pattern of mothers' love and care for children is surely not only true for Mexico, or Latin America, rather it is a universal human feature, most often labelled *maternal instinct*.

Scheper-Huges has criticised the use of this notion, arguing that maternal thinking and practices are *socially produced* rather than determined by a psychobiological script of innate or universal emotions. I would modify this stand a little, and say that the fact that variations of these – in lack of another word – instincts are found cross-culturally, seems to imply that a psychobiological basis do exist, but the scripts are given unique socio-cultural and personal forms. In her essay *Culture, Scarcity, and Maternal Thinking – Maternal Detachment and Infant Survival in a Brazilian Shantytown* (1985) Scheper-Huges reports

that "Mother love" is a commonsense and richly elaborated motif in Brazilian culture, for example demonstrated in the continuing folk Catholic devotion to the Virgin Mother. Nonetheless, selective neglect, accompanied by maternal detachment, is widespread among poor people in Scheper-Huges' field region. She argues that relative maternal indifference and neglect is understood as an appropriate maternal response to a deficiency *in* the child. Part of the *mother script* here is in other words knowing when to "let go": when to let a sick or starving infant, who does not show appetite for life, die.

For my Mari "letting go" of any of her chronically ill sons seemed never to have been an option. Still she imagined how her life could have been, if her boys had not been disabled. What she emphasised was the freedom that would have implied, because their relationship of dependency is a two-way-street. She felt just as dependent on providing them, as they were dependent on her support. What was being exchanged were material and services, but the transactions were filled with emotions and sentiments.

Margarita: How do you think your life would have been if your sons had not got this disease?

Mari: Well, I think it would have been good, because I would go everywhere, visiting. Because when they cannot walk, there are problems with getting a car (*colectivo*). There is no car for him, and we have to wait for *el transporte* (usually pick-up), and often they won't let us. There are some cars (drivers), who might drive us here, but others won't, because of the (wheel)chairs. Bowel, who died, that one did not charge me much; like 10 pesos for Mateo. That is why it was better with Bowel, but now he is not here anymore.

Margarita: I see. How heavy that was also, with the bereavements.

Mari: Yes, but here... (that happens), because some times there are men that you know have got a wife. And that (*infidelity*) is no good. If the *señora* has got a husband, she should not behave as a thief: then she should stay with her husband. Because if she has got a husband, he might come, and if he sees them is the act, well: then it is better to kill them, if he doesn't approve of what is going on. There are some who does not do anything, they just leave, without even rebuking their wife, they just take their things, their bags, and take off: Each one for his and her own life. Then she is left, unattractive, but without staining her hands.

Because if one kills, one will go to his country (*hell*): and then one will never ever return. Well, that would be what I would do, if I were a man. I would kill the other guy. I would kill him here, and then escape. But only alone: without having a family. Because when one has a family, one has to feed his or her children.

Margarita: Yes. But there are many men, and many drunkards here, who does not take that responsibility.

Mari: Ah, they don't think, you know. Just like the one who killed: he did not like to sustain for his children.

Margarita: No, that's what I saw (*I always saw him drunk in town, and I did not think he had a family*).

And then Cassandra was the one supporting her husband's drinking, wasn't she?

Mari: Well, she was, but she was also fooling around, as if she didn't have a husband. Then it is better to stay alone, like me, better alone. Then one won't be staining one's hands with anybody. Or none will say that "I killed the other guy because of you". It is better to stay alone, so you won't stain your hands.

Myself, I don't want to have another's life: to be a slave, and have your husband following after you in your life. Then the wife will be working, but he won't. Men want everything for themselves. That is how the Mexicans are here. Well, not everybody, but several.

Margarita: Aren't you exaggerating?

Mari, laughing: And some times they care for the foreigners because of this (*and she shows the money sign with her right hand*), they don't love them because of tenderness, but for interest. They love him or her (the foreigner) because of the money. And many people marry a foreigner, because they know that they have (money).

If they marry a woman from here, she will be poor: she won't have money. And sometimes they even leave their wife to go with another, with a foreigner.

Margarita: Well yes, it seems like here in Aguatepec a lot of the guys, or youngsters, look for a wife or a girlfriend.

Mari: They want foreigners! It's because of the same thing, of course. When one care for each other; it should be because of love, and nothing else. Just like one is poor, the other one can be poor, because money is nothing in life. Money will vanish. That pride (from money) will vanish, one won't have it all of one's life. Money is money: It will just disappear.

Money does not necessarily give you anything. It depends. For one part it is better not having anything: one won't stain one's hands. Or join together with a companion who is poor, as well. Because some do it just because of this (*and she makes the money sign again*), nothing else, they don't do it because they love you. As if that's why they show it in the *telenovelas* sometimes; so that people see, that there are mums who are so poor that nobody takes notice of her. As it is in one's own life.

Margarita: Yes. Life is a grand *telenovela*.

Mari: Yes, and that's why they show it in the *novelas*, so people see how it is, so that men can open their eyes. With money, you know; you can call for everything to be done, this and that, but when everything is done, what then? You are left with nothing!

Margarita: Yes, so you don't think it would be glory to have money?

Mari: Well, yes it is good to have money, but it must be clean! If one is lucky, and marry a foreigner, well let him join her! If a man has got luck, it is his own luck, that's how it is.

Mari is discussing the cultural scripts of women and men. From her point of view love and responsibility towards ones children should force parents to calculate risk, but as Mexican men often fail this conviction (because they in general are lazy and egoistic, she claims), it is then up to the women, as mothers, to measure and avoid risks. Mari consequently expresses dismay about her previous workmate Cassandra for engaging in a love affair outside of marriage. She should have known better. Although her husband was a demolished drunkard, the wife had the responsibility to stay with him, in order to stay clean, and not stain her hands, not least out of security reasons. Mari highlights the husband's customary liability to punish his wife by killing the lover, by noting that she would have done just the same thing, were she a man.

Men are also more easily blinded by money than women, and Mari seems in a sublime way to embody what Stevens called women's spiritual and moral superiority over men (1973:91)(står 1971 i ref list). Her statement about money's temporality also mirrors Foster's "Peasant Society and the Image of Limited Goods" (1965), as well as her thoughts about luck. Foster said that within the cognitive orientation where peasants saw anybody's accumulation of wealth as a treat to themselves and fellow

villagers, the only “great success” that could be approved of was that “obtained by the favour of the saints, or by luck, certainly not by thrift, work and enterprise” (ibid: 307). Octavio Paz, in a preface to Lafaye’s treatise on Mexican consciousness, wrote presumptuously that “the Mexican people, after more than two centuries of experiments and defeats, have faith only in the Virgin of Guadalupe and the National Lottery”.

Margarita: Did you know many other persons with disability earlier, other than your own sons?

Mari: Well, when I came here I got to know many, but not day by day in Comintla: no, nobody. Not then, but afterwards. Although there are many mums who go hiding their child, and they don’t let them out in public, so people can see them. Like Mateo, who I am hiding here, but it is necessary. But over there, in his own place: Looking TV, because that’s his interest.

He doesn’t like exercises! Yesterday he hid himself. He didn’t go to do his exercises with Estela. He prefers to stay watching TV, so that Estela doesn’t see him. And I, well: I want him to go! I reprimand him when he doesn’t. So that he can improve, so that he doesn’t stay like he is. If he doesn’t; later he won’t be able to move himself. He will stay merely in bed. And then he will... (fade away). I want him to go out, to laugh, to see, like he did in the beginning, then he went out to play. Well, he likes the (public) parties, and going to *rosarios* (ceremonies held in connection to deaths), but he just goes there, because he doesn’t eat nor the *tamales* nor the bread. He doesn’t eat anything at the *rosarios*, he just like to go there. To a *baile* (dance party), he likes to go, when he knows that I am going; he doesn’t sleep at night!

Then he starts crying, so that I will bring him with me, saying; “no, you are fooling me, you are going to that place!” “Yes, you have to go, because you have to go”. He doesn’t let me miss out, and it’s no use saying that I’m tired, and I don’t want to go. “No, man, if you are going, I will also go, if not: I won’t let you go!”

That’s how he is. He doesn’t let himself with nobody else here, not even with his sister!

Margarita: Did you know his disease earlier?

Mari: No, not at all.

Margarita: So you didn’t have any familiars who suffered from the same?

Mari: No. None.

Margarita: Aha. Do you know what the disease is called?

Mari: It is muscular... yes. Here they did an operation on him, (*pointing to her eye*) to see how they could cure him. But he didn’t let himself anymore after that. He fell really ill that time. It was before Felix died. What happened was that the injection nail got infected. He had an inflammation here. It got infected. That was when they made him that study in his eye. After that, he didn’t let himself anymore. They used to give him therapy here, so that his legs should keep straight, so that they don’t do this (*she crumbles her legs up towards her body*) with the time passing.

It was a therapy on the floor. Now he can’t do it anymore, because his legs are stuck to his heart, and now they can’t be pulled out. With the other one it wasn’t possible either. His legs were also stuck together. And then there was no remedy. Once that they wanted to recuperate Mateo, but then I didn’t want to try anymore, because I thought: “and if he dies there...”

No, I prefer to bring him with me in a wheelchair, and not that I should see him under the ground. You see? And I was quarrelling with the doctor. I said no, no, no! And he (the doctor) also said that it wasn’t sure, and then the two of them... Even Mateo said “they will kill me”. “Yes, You will kill me, if you let them operate on me.” “Then I won’t see my mum anymore, *y ya* (that’s it).” He didn’t want to. They were mad at me; you know (the health staff). They told me: “Now

your son won't walk." "He has to stay like that, and so it will keep on." But it doesn't matter that he is in a wheelchair! What I want is that he will still be alive, and not that tomorrow they will be reproaching me saying that because of the operation he died. And until this date he is afraid of any operation: "Why did they cut me like this?" he asks. "Why are they always cutting in me?" And he didn't let them. I didn't want it either, that's true.

Being a mother today, Mari's different choices of action appear more reasonable to me now. In the field, I remember I personally thought Mari had made a bad choice when she had not allowed the doctors to operate on her son. Then he might have meliorated. Just like the professional health workers I had seen the option of improvement as carrying more weight than Mateo's life. Mari, as mother, regarded the situation differently: she wanted to protect her son against possible injury and death, even though this choice simultaneously took away his possibility of a temporarily melioration. What all in all made her choice morally right, I believe, is the fact that Mateo himself did not want the operation. He also emphasised the risk the operation would imply, what is absolutely reasonable in view of the little test he had previously undergone, which had failed and caused an unintended infection. What kind of guarantee did he have that a full-size operation would go any better? Although the doctors could not assure the outcome of the operation they tried to convince mother and son. (From own experience I know that one can easily become slightly paranoid in such a situation, where one is without control, and) I imagine Mateo's fear that the doctors would in fact kill him, what he also told his mother explicitly; *me van a matar*, they will kill me. He also claimed his mother to be guilty if she let the doctors have their will: *Usted porque es asi, pues* (You, because you are that way). Simultaneously, the health staff blamed the mother for not wanting to help her son, implying that she would be responsible for her son's failure to walk.

Thus, Doña Mari was in a situation of incompatible pressures. She was not comfortable with the health staff's critique of her choice, but passivity was an active choice. She feared losing her son ahead of time, as well as she feared the possible reproach from the community if she admitted an operation that failed.

Before I came down for my second fieldwork, I knew that Mateo had recently died.

Tuesday November 1st I arrive early at the rehabilitation centre, as I know they will have their weekly assembly. The meeting is both interesting and fun, and afterwards I sit down to record it with the help of the board leader Cantinflas' papers. After that I just hang around. These days everybody are busy with the preparations for *el Día de los Muertos* (the Day of the Dead), which is tomorrow. The preparations for the *Altar (de Muertos)* are ready: I see the arced wooden framework I know will be adorned with flowers for tomorrow. This night they will also prepare *tamales*; traditional corn bread that are baked in their own leaves, which is typical food for this celebration.

I wanted to see how some of my informants relate to, and celebrate the Day of the Dead. Therefore I talked to Mari and got an appointment with her for next day. Mari said she was going to the new village cemetery next morning, to see her youngest son, Mateo, and in the evening she would go to the cemetery in Puerto Santo, the neighbouring village, where her oldest son, Felix, is buried. Actually she would have liked to go today, she explained: since this is the day for the young and innocent dead, the *angelitos*, but she would not be able to leave work, and tomorrow is everybody's day.

Next day I met Mari in the morning in Palapa Papaya, and we agree to meet at the cemetery later. In Palapa Papaya the *ofrenda* to celebrate the dead is ready, and it is occupying the main wall in the circular *comedor*. The *altar* is splendid, and quite typical for the region: A wooden arch covered with orange and deep red flowers, and on the table lots of fruit, mainly oranges and bananas, which are also hung up as adoration. The cooks are bringing more food there; *tamales*, and there is a joyful atmosphere. People are smiling, laughing, and admiring the *ofrenda*, and *the Virgin of Guadalupe* is looking down from a frame in the middle of the *altar*.

Día de los Muertos (Day of the Dead)

((I have climbed up the steep main road to the cemetery in advance, to visit some friends where I can leave my baby for a while. The family is occupied with the creation of a small private *ofrenda* outside their house. Interestingly, it is two of the sons of in the family, who are both young adults, who are engaged in this work. Down at the centre this was the women's task.) Not many people pass by here, and I know there is also a shortcut up to the cemetery from the other side of the village, and I wonder if Mari might have taken that way? After some time I nonetheless hear somebody calling my name: "Margarita!" It is Mari and her daughter Dinah, who are coming up the main road, together with Lizeth, a young special teacher who works in Palapa Papaya. Now they are all passing by the house where I am at. I am happy to see them, and run over to join them. (It is a good time, because my son is sleeping.))

We walk up together, and Mari then stops by the next house, to leave some *tamales*.

To my surprise there are nobody else at the cemetery when we arrive, but there are flowers on most of the graves. Mari and Dinah bring flowers in a bucket: they wash Mateo's tomb, and put orange flowers in vases upon it. His tomb is simple, but Mari explains that she wants to cover it with fabric later on, when she can afford it. We spend some time on his tomb, and then go around seeing other graves.

After a while I find Mari occupied with a tomb on the other edge of the cemetery. I go over to her. "This is Amado's tomb," she says, and I also put a small flower upon it. I knew Amado as well, from my first fieldwork, when he was living in Palapa Papaya. He was a teenager who had a brain damage, and he was dependent on support to manage daily activities. At that time his sister Paloma, who was just a year or two younger than him also lived at the centre, together with their cousin Dolores, who was Amado's age, and her father Tito (see Chapter 4). Amado always seemed to find great joy and pleasure in his sister. He was not talking, but he used to smile and laugh whenever she was around.

Amado's tomb is plain, and without any cross or adoration. That is according to his family's religion, I am told. "They do not want any adoration here," Mari says.

Mari brings a small bucket of water which she spreads upon the tomb: "So that Amado can refresh himself a little bit," she says. Dinah comes over bringing some left-over flowers, and they now adorn the simple tomb briefly. Mari subsequently forms a little cross out of flower petals, that she lets fall upon the cement cage. "God forgive me, or Amado's family forgive me, because as they are *Evangelicos*, they don't like the cross." "No, they don't want anything to adorn their boy's tomb, but I do it, nonetheless." "Because I know that they won't come here, as they are in the United States, and Amado's uncle Tito doesn't visit the tomb either."

El Día de los Muertos is a typical Catholic day, mixed with pre-Columbian traditions. *Los Evangelicos*, that is; people from non-Catholic congregations or "sects", do not celebrate this day at all, nor any Catholic Saint's day. Tito, who is head of the local subdivision of Jehovah's Witnesses, does certainly not engage in such celebrations.

Early this summer Amado died, of pneumonia, though Mari believes it might have been out of sadness and longing for his family. To everybody's surprise Amado's father actually turned up for his son's burial, and he stayed some time with his brother Tito, before going back to *el norte*.

Afterwards we go around watching the graves. There are not many, as this cemetery was opened only four years ago, in fact during my field work: I remember that *El Coco*, one of the drunkards of the village was the first one to be buried here. I also remember the wild eyes of another drunkard, *el Cohetes*, when he was shooting up explosives at the entrance of the cemetery on that occasion. He had been swearing that this one should not be the last. Some days later the next one was actually buried here. The taxi driver Bowel had been murdered while in bed with *el Cohetes'* wife.

We go around looking at the graves, while remembering the different persons who are now dead: Bowel, El Coco, the *curandera* (healer) Tía Adolfiná. Then we go back to Mateo's tomb which is located near the entrance of the cemetery, we make the cross' sign, with various degrees of precision, and we walk out.

More people are coming up now: I see the big truck of our neighbours with a lot of family members coming, and a man in a tanker is depositing water in two wells inside the cemetery. Now Mari goes down to Palapa Papaya to do some more cooking, but we agree to see each other in a couple of hours in the cemetery of Puerto Santo.

(At my friends' house the boys are finished with the *ofrenda*. It is now adorned with more flowers, and they have put fruit on the table: *limas* and bananas. There is also a picture of the Virgin of Juquila, which normally hangs on the kitchen wall. Earlier, when the family was poorer than they are now, they could not afford making such a big *ofrenda*, but now they seem proud to show off this one.

After eating and feeding my baby I decide to go to the cemetery in the neighbouring village. I take a taxi, as I do not know when the people from Palapa Papaya will come, and possibly they are already there.)

Arriving at the cemetery in Puerto Santo I am overwhelmed: It is so crowded! How will I be able to see anyone? I decide to relax a bit, and get myself a delicious *horchata*³⁵, great for the heat outside the cemetery, where various stands have popped up, offering food and drink to the visitors to the graveyard.

The cemetery is located in a steep hillside and when I enter I have to be very careful where to put my feet, because the paths are rough and stony. I know that Mari's son Felix is buried high up, together with Palmer Brown, the founder of Palapa Papaya. After some looking around and asking people, I am able to find the site. It is a pretty big and high tomb, not of the most impressive, but much bigger and nicer than the tombs I went to see earlier today, in Aguatepec. Nobody else is there, and there are no fresh flowers on the tomb. Therefore I climb a bit higher up, where I can see there are some wild flowers growing on the side of the graveyard. They are small, but of the right colour (orange), and I go and pick some, which I put on the tomb, and I sit down and wait.

Most people are gathered close to the entrance further down, where there is also an outdoor church: just a facade with a kind of stage in front of it. But there are also some families coming up here to visit their tombs, so there are plenty of small happenings to watch, and people to interact with. After a while I hear well-known voices, and I can see a big group of people from Palapa Papaya climbing up the hill from the side. First they rest outside a nice house that lies just on the other side of the path from where the tomb is. I thought that house might be the residence for the parish' priest, because it has the view all over the graveyard, and further down to "Playa Necropolis", but when I inquire I get to know that it is a private house that is rented out for tourists.

The group from Palapa Papaya counts about 20 people. Sara and Chico are carried up here, by some of the volunteers and a foreigner friend, as they can not walk and it is impossible to manage a wheelchair here. Both Sara and Chico are brought up in Palapa Papaya and therefore they knew both Palmer Brown, who adopted them as his own children, and Felix, who lived at the centre for many years. The two youngsters are accommodated on a blanket at the foot of the tomb, from where they have a good overview of what is happening.

Doña Mari carries a big bucket of orange flowers, others bring candles, and Roberta, the current leader General Coordinator of Palapa Papaya brings an enclosed bucket of glowing *copal*³⁶. Tía Amelia, who has worked as cook in Palapa Papaya right from the beginning, helps Roberta to put copal on a metallic golden balance, and then Roberta goes around to everyone sharing the smell, and perhaps also rinsing our interior.

Mari has climbed upon the tomb, and people hand over flowers to her so that she can adorn the site. Her daughter also climbs up for a moment to help her. Beneath the tomb the group of people are talking, joking, smoking and enjoying themselves. Most of the volunteers have brought their cameras, and just as them: I take advantage of the situation to take photos. Afterwards I follow doña Mari, Dinah, and tía Amelia down to the centre of the cemetery where we attend a Catholic mass in front of the church façade. Lots of village people are present and attend the mass: Some are doing so from their own family members' or friends' graves. I notice that these women seem to put more dedication into the "Ave María" than the "Padre Nuestro": they pronounce the former oration more intensively and louder than the latter, and it sounds like this is the tenet.

The rituals surrounding the day of the dead are popular cultural manifestations all over Mexico, and it is often claimed that Mexicans have a special, somewhat morbid relationship to death (Brandes,

35 A homemade and spicy rice-water.

36 Resin taken from pine wood which produces a strong but pleasant odour when it is burned, much used for ceremonies.

2003:1).³⁷ Mexican and international writers and scientists have followed Octavio Paz' ideas in his famous essay collection *The Labyrinth of Solitude* (1961) about the "Mexican National Character", which include, among other characteristics, that the Mexican are obsessed with death and celebrate it. And this, Paz argues, is because "Mexican death is a mirror of Mexican life" (Paz, [1961] 2005:58). It is difficult not to agree in such a general statement, which can also be claimed about many other peoples of many other nation-states.

National Characters arouse as object of anthropological study in the US during and after World War II. Since 1939 Gregory Bateson and Margareth Mead, among others, took part in setting up a "National Committee for National Morale", with the object of producing a study of own national culture that could lead to recommendations for keeping US morale high during the conflict (Neiburg and Goldman, 1998:56). After the Japanese attack on Pearl Harbour in 1941, members of the Committee, in direct agreement with the US Navy, would also seek to contribute to a better understanding of allied nations and, especially, of enemy ones.

Today "National Characters" is no longer sustained in the social sciences as a pure object. However, Bourdieu says that "analyses of national character reveal that any account of "national phenomena"... implicates, in its very formulation, statements endowed with some level of performative efficacy: any description that gains recognition will be destined to form part of the thing it describes." (Bourdieu 1981, cited in Neiburg and Goldman, 1998:72)

Octavio Paz' work on Mexican National Character has undoubtedly contributed to the existence of the very thing, along with works of art, politics and popular culture.

The Day of the Dead, as manifestation of popular culture, has been highlighted and expanded also by national and local politicians, as the celebrations are attracting visitors in great numbers, both nationals and internationals, and it has become an international symbol of Mexico. Stanley Brandes (2003) argues that "it is the popularity and commercial promotion of the Day of the Dead that is largely responsible for creating the essentialist image of a macabre Mexican".

However, what matters here are specific persons' relation to this day and its rituals. For persons who are mourning the death of a dear family member, (the) rituals serve a number of functions. The Day of the Dead can be seen as a special instance of *secondary mortuary practice*, where the public functions might be easiest to observe. I will nevertheless give special emphasis on how the rituals connected to this day are made meaningful by and for individuals.

Doña Mari's visit to the first cemetery, where her youngest son was buried, seemed to be of a very personal concern. Her youngest daughter, who had interacted intimately with her brother Mateo

³⁷ See for example Stanley Brandes' "Is There a Mexican View of Death?) for a discussion of the creation of "The Mexican National Character".

throughout their childhood, was also an active companion, assisting her mother in washing the tomb, in order to cool Mateo from the burning sun. Later Mari repeated the same process on Amado's tomb, terminating the process with creating a small cross out of flower petals. She seemed to be moved by deep personal forces, towards the boy, who she had been seeing and feeding for many years.

Mortuary rites have often been analysed for their enforcement of social ties between the deceased's family and the rest of the community, especially a husband or a wife's family. Participating in such rites means respecting the deceased and recognising his or her family. When Mari approached Amado's tomb it was not a show. It was not something she did to recognise or be recognised by the child's family. To the contrary: nobody was there to give social recognition for her acts, and she would not have acted as she did if the child's family were to arrive. If Amado's family had seen her, they would most probably have reproached her acts harshly. But Mari acted as she did because this is what she felt like doing. It is a cultural practice that she is highly reflexive about.

The visit to the next cemetery takes the form, primarily, of a collective ritual. Here Mari is also central, as the closest family member of any of the two persons buried in the tomb and commemorated in the moment. Initially, when the mourners and spectators were gathered around the tomb, the centre's leader; herself an anthropologist, clears the arena, spreading smoke of *copal*, a traditional incense, employed for ceremonial uses of different kinds.

Roberta, like myself and the volunteers present, did not know any of the deceased whom we were commemorating, and it might have felt strange, or as an abuse of power, both to Roberta herself and the other participants, had she continued as ceremonial master. However Mari takes over, climbing upon the high tomb. Her daughter Dinah, and the oldest resident and worker from the centre, tía Amelia, assist her, handing her flowers which she uses to adorn the tomb. She lights a candle inside the upper wall of the tomb, and then descends. No speeches are made, other than informal chatting by the spectators, and practical advices on how to put the flowers.

It is significant that also a couple of the permanent patients take part in the ceremony. These two youngsters enjoy participating in most activities arranged by the centre. They are communicative, bright and sensitive, judged from their easy taking to laughter and tears, and their production of comprehensible corporal signs. Though, they also have got severe problems linked to their disabilities (cerebral palsy); they can not speak, walk, nor eat for themselves. They had to be carried up steep paths in order to get to the tomb, and they seemed to love the adventure, laughing and smiling. When they arrived they seemed relaxed and satisfied, lying down on a blanket on the ground, from where they had a good view up to the tomb. Palmer Brown, the founder of the centre, was their adoptive father and a most significant other to them personally. He is perhaps the reason that they are still alive, as they both came to the centre

severely malnourished, from families who could not provide for them. Also Mari's son Felix, who is buried together with the founder, was their companion and friend.

There are hundreds of tombs at the cemetery, and crowded with people, who all perform their own rituals, almost everybody in family-groups.

Later, the communal ritual, the mass given outdoors, is tying the different participants together. The passion with which the "Ave María" was pronounced was unmistakable, and seemed to confirm their identification with the Holy Mother and her suffering for her son.

After greeting each other and other participants heartily at the end of the mass, we climb up to the rest of the group. Sara is not feeling very well now, and it is rapidly getting darker, therefore we all decide to go back to Palapa Papaya. We carry all our things, plus Sara and Chico, down to the bottom of the cemetery, using the same path as they did for climbing up. It is not any easier to walk here, but we emerge in a different and noiseless place, where they have their old Volkswagen mini bus and a pick-up waiting. (I am lucky enough to gain "an honourable seat" inside the bus between the two cooks *doña* Mari and *doña* Amelia.)

Inside the bus the two ladies talk about the last day of the dead *el día de los muertos de mala muerte*, which is one week ahead. It is known as an especially loaded day, when the ones who have suffered a violent death; the ones who were murdered and can not rest, are remembered. This day ends the celebrations and everybody takes down their *ofrendas*, they tell me.

A couple of weeks later, Mari and I sat down for an interview.

Second interview with *doña* Mari

Margarita: How do you actually feel now?

Mari, with tears in her eyes: Well, finally I feel rested, now that they are not here anymore. Both my sons have died now, and now it is just Dinah who stays with me, no one else.

Margarita: I see that you get sad when you think about the two who are not here anymore.

Mari: Yes, but it was a heavy burden on my shoulders, to care for the two of them. I was very dependent then, and for them; now they did not have to suffer anymore. Because they were suffering; just like I was suffering; they were too.

Margarita: I only knew Mateo, but I feel that I knew Felix as well, because of the mural paintings that he designed, that are still brightening up the surroundings here, and what people have told me about him, that he was a happy and smiling boy who liked to make other people laugh.

Mari: Yes, the mural that is just over there: he made it. Must he rest in peace! The one who didn't like painting was Mateo. Mateo liked to watch television. That was all he liked: comics. He liked to visit Tia Amelia, because she had "Sky", and he liked to watch that. The blessed Felix liked music. He also liked to go out, to promenade, while Mateo did not, as he withdrew into himself after a while, and so he let in the sad part.

Margarita, smiling: Yes, I remember: Mateo had a very strong character.

Mari: Yes, that's how it was, but I was surprised that he was quicker to leave than Felix: Felix lasted alive for longer than Mateo. Felix was 20 when he died, and Mateo died when he was about to celebrate 17. He died three days before he turned 17. I don't want to cry, because I have got three left, but...

Margarita: I understand.

Mari: All three of them are doing fine. Eddie is doing well in his studies; he is staying in Oaxaca, now.

Actually he did not want to go there, but I told him it would be better if he did. He wanted to go to Tuxtla, (the state capital of Chiapas,) but that is very far away, and the money is expensive. He would have to pay 2000 pesos per month! And in addition was a room to stay, and living expenses, with everything it would have been 5000 pesos. So he couldn't go there, but he went to Oaxaca.

In the article "*Female Altruism Reconsidered: The Virgin Mary as Economic Woman*" (1982), Browner and Lewin argued that Latina mothers, both in San Francisco, USA, and Cali, Colombia, acted economically strategic in regards to emotional involvement in children or partners. Caleñas tended to use a "beauty queen"-strategy to conquer and "keep" a man, and hoped to be partially provided by the man, as a way to ensure economic survival. They therefore spent much time and involvement on the man, and on manufacturing themselves as sexually desirable, and in general less on children than their San Franciscan counterparts. These, Browner and Lewin argues, view the mother-child relationship as more instrumental: "San Francisco Latinas are more likely than Caleñas to believe their children will make a long-term economic commitment to their mother's economic welfare because they feel that opportunities will be open to their children later in life. ... The dream of upward mobility gives mothers the hope that a stable source of finance will grow directly from these emotional bonds." (1982:67).

In my field, the dream of upward mobility did not seem very strong, although mothers, as Mari, do emphasise the value in children going to school. But when Mari put so much effort and emotional involvement into her disabled son's, this was primarily an emotional and moral strategy, which did not mean money. Mari emphasised that she was dependent on them. Although she in some ways was constrained by their dependence, this provided her with emotional and social meaning in life.

Providing and caring for them was meaningful to her personally, but also socially, and she adapted a cultural model available. Acting the way she did also bestowed her with social recognition and dignity.

Margarita: Do you feel that life is easier now?

Mari: Yes, because if I want to go somewhere, I can just do it. I don't have to think about Mateo. Earlier, I always had to arrange things, if I would leave him: who should care for him in the meantime? If I were to go to Oaxaca, who should stay with Mateo? There were no one, and I had to bring him sometimes. There were times when I saw that it would be very difficult for me, because I had to carry him. I brought him here (*and she shows her lap*); and I could not move at all in the bus. Once he was hurt after a bus ride like that.

Margarita: How are you as a person?

Mari: Now I am peaceful, I am good. I like to travel a little bit, but not too much, because my daughter is in school. I spend my spare time with my daughter, but when she ends secondary school it might be different. She will study in the same school as her brothers did, in Puerto Santo, because the school in Comintla is more expensive. One has to travel

longer, and sometimes there are reunions, and it is far to go to Comintla just for a reunion. It is better here in the neighbourhood. It is easier to leave for a reunion, and Irma (a fellow worker) can step in for me.

Margarita: What do you think has influenced you most to be the person you are?

Mari: My children. They started school here in Palapa. If we hadn't come here, they would have died a lot earlier. The young ones: they wouldn't have kept alive. Here doctor Flavio was always looking after them. Thanks to the medicines they stayed alive. Who knows what would have happened if we had not come here? At least I think that my children wouldn't have gone to school.

It is evident that Mari, as primary care-giver and consequently model of identification, has influenced her children, but she chooses to focus the other way around, stating that her children are the ones who have influenced her to become the person she is today. What is implied is that their very being has compelled her to act just as a mother must do, according to the cultural view explained in her own moral argumentation during our earlier interview.

Margarita: How were you treated as a kid?

Mari: They did not send me to school; and that is why I oblige my children to go. "I did not go to school," I tell them, "so hurry up, now it's late to do the homework". And I order them to walk there rapidly, because the teachers will reprimand them if they get there late, and then I will say "why do you make me suffer?" I want them to step forward in life. Keep on forward, and suddenly, the day after tomorrow: Dinah will start working, because she knows how to study; she can read and write and count and everything. Myself; well, I don't know anything.

Margarita: How did you educate your children?

Mari: Like any mother. Admonishing them from time to time, telling them not to stay out late at night, for example.

Margarita: How are your relations with your broader family? Your parents?

Mari: None of my parents are alive, and I never had a father. Both my parents died while I was little, so I never knew them. Another woman raised me. My social mother: not my real mother. She adopted me, together with her husband. Her husband died, and now she is also an old woman, who doesn't see any more, because they made an operation to her eyes. And her vision wasn't any better, rather to the contrary; they made her blinder. It is over for her, because she is totally dependent on others. Some times she lives a month with one daughter, next month with another, and so on: from house to house. She is led in the arm because she doesn't see anything, but she doesn't stop eating; she eats a lot!

The only problem is that they removed her sight, because she could see with one eye, but after the operation everything got more complicated. I told them not to complicate the situation with an operation on an old woman, while she actually was able to see. She was getting around, you know; with a stick. She did not stay in one place, but wandered high and low, she was like a whirlwind.

But now that she is blind, she can't do that anymore. I haven't gone to Toyula lately, so actually I don't even know if the old one will be there, or in Nisatulco, or in Oaxaca. Who knows where she is at?

I haven't been there since my stepsister died. I don't remember what month she died, perhaps it was in April... Anyway; the mother thinks that her daughter still is alive, because they haven't told her. I believe it is wrong of them not to tell the old woman that her daughter has died, but it is the responsibility of her children, and they don't want to tell her.

Margarita: Well, then the mother will definitely end up very confused.

Mari: Yes, but her children won't tell her. And so the old woman always keeps asking for Clara, because that is how her daughter was called. "Who is there?" she asks; "Clara, Clara?" But she is not there. Clara died, but the mother is still closer to Clara than to anybody else.

Mari makes moral complaints about how the woman who brought her up is being treated on her old days. However, since the old one is not Mari's biological mother, she does not have a say towards her adoptive kin, she explains. Mari emphasises the old woman's dependency on others, and it seems that she evaluates such dependency, without loving care and affection as a real misery, in contrast to what she and her children experienced.

Margarita: Have you been able to realize some of your plans and hopes for your own life?

Mari: Hopes for my life... With time I am thinking about putting up my own house, within three years time, hopefully.

Margarita: Yes, that is what you told me about the other day. (*When we took a taxi together to Comintla she pointed out to me where she had bought a small piece of land.*)

Mari: Now I want to set aside some money, and get started as soon as possible. The problem is that right now there is no money. The little that I earn I give to my children for schooling, and it isn't even enough. But I want to save a little money further on, and make my own house, nothing more. Then I will go there to live, though I might still come here to work. Or perhaps I will make the house, and then rent it out, if I want to go to Oaxaca, or if I am given another opportunity. Well, now I have got the papers at least. Now I want to send somebody to clean the ground there; my children, well that is those who are left; because my two sons died. The terrain is not that big, but it is good for putting up a house and live there. My oldest children have got their homes already, so they are not concerned.

Mari makes a point out of always remembering all her children, dead and alive. However, now that she is no longer constrained by the extra work that her deceased sons represented; she is also seeing new possibilities. Through the little piece of land that she has bought, she wants to generate independence for herself, and she is planning to set up a house. Now it becomes apparent that she actually believes in her own workforce as a dynamo for change. If she inhabits an "Image of Limited Goods", this is only partially, and she is free to use another and more progressive mentality as well. She has also gained some weight, what seems like a result of the ease of pressures she now experiences.

Margarita: Now your boys are not here anymore, but I see that you have got much love for the other children here in Palapa.

Mari: Yes, for the other children; that is true. It comes naturally, because I live here, because I don't have a house on my own. I am living here, in this room, but when I get my house, I will leave. Perhaps I would come in the afternoons, or in the mornings... The thing is that the ones who live here; also have to work in the night, so then I will not have to do that.

Now Mari wants to enjoy the independence that she has earlier dreamt of.

If it is so that her children have made her the person she is today, Felix, with his optimism, seems to have had the strongest influence on her. Though, I do see both her boys in her; both optimism and pessimism, joy and sadness.

Margarita: How did you find out that your sons had got a disease? What happened?

Mari: Well; Mateo, the youngest one did walk, but the case was that he had a strange lump that grew on his back. Are you sure that he did not walk, by the way, when you were here?

Margarita: Absolutely.

Mari: Well, first he was crawling, but he did not really help himself with his hands, you know, and therefore he crushed his head... But later he learned to walk: He walked. Well both of them walked. Too bad I haven't got any photos, it is possible that Teresa (the former leader of the centre) has, but myself I haven't got any. I have not got any photo of them when they walked...

Sometimes they used to sit down, to paint. In front of a tick paper they could sit down, or they could sit down and play with small cars. They went crawling; over there (she points at the open space outside the kitchen).

Felix was the first one in my family to come here to Palapa Papaya, and he was walking when he arrived here. He was six years old, and he came alone. I came to leave him here alone, and afterwards I came to visit, but he did not want to stay here alone; he cried, I remember. When people asked him why he was crying, he said it was for his mum, because she had left him: "That is why I am crying", he said. He did not want to go to school, because I was not there for him. He started to hide himself, and he said he went to school, but it wasn't true, he didn't go there. He hid himself until he heard the children come back from school, and then he popped up, but he didn't go to school, because I was not there, not until I came.

Margarita: And then he did go to school?

Mari: Yes he did; but only once. The other kids had thrown him down, and then he had left. Rita's son threw him down from school: the school is up on a small hill, you know. He was mistreated when he came back to Palapa, because he had been tied to his wheelchair, and if they had not secured him, he would have fallen out of the chair, and then he would have killed himself right away, there! He was almost more dead than alive when the teachers brought him back here.

What happened was that he started to play, and he said; "hey little one!" and the little one hit him in the face, then Felix raised his hand, and in that the other one let go of the wheelchair, and then when he was rubbing himself he saw the chair speed away downwards.

Almost dead: they left his eye very bad, violet it was, because he fell – clap – and after that he didn't want to go to school any more. He dropped out. After that they gave him the opportunity to go to the special education school, and he went there, together with Sara and Chico, and later his brother Mateo, but after Felix died, Mateo did not want to go there anymore, because the other children hit him a lot, he said, and they spit at him.

He said "I don't want to go to school no more; I won't go any more to the special education school, because there they are not caring for me". "The little ones hit me, and no one protects me, they hit me all over" he said. "And now that my brother Felix died, what am I going to do?" "Felix is not there any more, and Sara already finished, Chico won't go any more either, and what am I going to do there alone?" "It is better that I don't go anymore, so it's better you take me out".

He also said that that school isn't worth anything; it is only for the wild ones. "No", he said, "take me out of that school, I don't want to go there", and what could I do? I had to take him out, because he really did not want to be there any more.

And he wasn't stupid; he won over me when it came to counting, he always knew the current day and date, and he remembered everything.

Margarita: Yes, he was very bright; I remember.

Mari: Yes, he knew how to count, and sometimes he studied on his own, and he used to go with Israel (a social worker in Palapa). But after a while; when he felt bad, bad, bad; he didn't want to go any more. He said; "what does it matter if I don't go, I won't to "El Palacio", any more, let me better watch television", and he started to watch TV, (*she smiles and laughs*).

Margarita: How has disability influenced your life?

Mari: One thing I must say first, is that it was very hard, because with two boys; it was hard.

My other children; well, they have moved forward, thanks to Palapa; that they opened their gates to me, and now if they had only given me a grant, I would leave. Now there is no one that can tell me not to go. Earlier they could, because my sons were here, but now that none of them are here any more, no one can tell me to remain. Earlier I had to stay on, but now that they are not here anymore, I will finish. I will come to an end, here.

Margarita: So you are you really thinking about leaving?

Mari: I will wait until my daughter Dinah finishes school, and then that's it.

What is constantly at stake for Mari, is her children's wellbeing and future. She does not seem to use her practices as mother instrumentally, as the San Francisco Latinas in Browner and Lewin's interpretation, but it can be claimed that she uses Palapa Papaya instrumentally, for the benefit of her children and herself.

An early afternoon in 2005, I sat down for a rest outside the kitchen in Palapa Papaya with tía Amelia, and we made use of the occasion to make a brief interview.

Tía Amelia – turning affliction to hope through personal struggle

Tia Amelia was a humble woman, past her childbearing years. She was the most senior cook at the centre, currently she was the only one in the staff of Palapa Papaya who had been working there from the founding days. As a widow, she has successfully brought up her three sons, and she dedicates time and interest in the wellbeing of all children at the centre. On special occasions she holds some ceremonial office here, spreading the air of *copal* in and around the kitchen area to rinse our souls.

Margarita: How did it come about that you started to work here?

Amelia: How..., well there was this Pablito (*the founder of the centre*); he started working here, little by little, and he cared for several kids and youngsters. Here it was only jungle on that time. After a while, when Teresa had just come here to work, because Teresa came here earlier than me, I went to see if they gave me a possibility to work. That was after I had come to Aguatepec to live, and my children had entered Primary School here. Yes, my children went to school, and then Pablito came to talk to me, and I came here to work.

Margarita: How did you look at the children, and grown ups with disability then?

Amelia: Well, we entered to work for them, so that they could capacitate themselves. It was for them we went to work.

Margarita: Yes. However I have often heard mentioned that people (*la gente*) don't support or approve of persons with disability, and things like that... What about you?

Amelia: No! I am not like that! I always prepared the food for Sara. Sara and Chico came here first, and Sara was so thin; every morning I prepared her *atole*, to give her *cosi*; to give her from her bottle. Yes, and Teresa cared for her; she put her on her back. In that way they went around. Chico here in front; and Sara on her back. Yes, I remember; and as there were not many here to take care of them; Teresa gave them their milk, and then they stayed here together with me afterwards. Yes, and Hector, my oldest boy, was looking after the place, and so on. After a while they went to look for a young man to watch over them, because it was a lot of work. That wasn't possible for us.

Tia Amelia seems happily devoted to her work. She explains her affection for the children with disability at the centre in a language of daily practices and work. Before mentioning her own children, she emphasises her closeness to Sara and Chico, the two earliest patients, who still live at the centre. Working and living at the centre is thoroughly meaningful to her, and she embraces the role she has as a substitute mother or aunt (*tía*³⁸) to everyone.

Margarita: None of your own children are disabled...

Amelia: No, none of them are. Two of them are still around, and they have finished their careers. Yes; one studied to be a doctor, and the other one physiotherapy. Yes, that's what they studied. Hector is in Mexico City now, in the *Teleton*³⁹. And Che, the youngest one, is working in a clinic in Jalapa. Then Chava (Salvador), in the middle, is living here, close to his mum.

Margarita: It seems like they were all influenced by Palapa; to work with people.

Amelia: Yes, and they were all both working and studying, and from they were small I brought them with me to my work here.

Margarita: And how do you feel here?

Amelia: Very good. Originally I come from Pluma Juarez, but we used to live in Montania. The father of my children comes from Paloatlan, though. He died, my husband, when my youngest boy was still a baby. He was 1 year and a month when they killed his dad. He was really little, Che, when they killed his dad.

38 In Mexico the term *tía* really means 'aunt'. It is generally not meant metaphorically, as in Spain, where it is used to address or speak of any woman or female friend. Thus the employment of the term here is a sign of *cariño* (love and affection).

39 A main fundraising campaign appointed to work in favour of children and youngsters with disabilities.

Margarita: Oh, that's too sad... did it happen in Montania?

Amelia: Yes, in Montania, because his dad started to work as a judicial. It happened after he started working there. It is very dangerous, you know. Especially it is dangerous to go outside. They must stay inside their offices, hidden. As he went out... they killed him. I was left with the small ones, and then however; I started working! (*Smiling*) Yes, then I started to work: I did cooking, and everything else, almost.

The story of the death of Tía Amelia's husband links social violence to personal suffering and struggle. Violence brings suffering which might inspire a struggle to overcome, or a struggle to revenge. Renato Rosaldo, in the introduction to his book "Culture and Truth", proposes that Ilongot headhunting might be motivated by affliction turned into rage by the participants (Rosaldo 1989, Spanish version: *Cultura y verdad*, 1991:16-17). Thus; suffering may also motivate violence, in the form of revenge, which can be both personal (vendetta), or impersonal, often as result of desperation.

Margarita: You always look happy; how do you feel as a person?

Amelia smiling: Well I feel good; happy working for the children. Yes, that's how I feel; washing, putting things into place, everything, and what is put there wrong; everything counts!

Margarita: Do you think you will continue to work here in Palapa for long?

Amelia: Yes, until I can hang on; until I drop! (*Laughing:*) While it works, and while I can still walk, I will keep on working!

Margarita: That's good! And have you seen changes in society, in the way of treating people with disabilities?

Amelia: Yes I have seen changes; because earlier there were more maltreating, earlier they got hold of more children who were in bad conditions, but now that they have spoken to people they are changing.

Yes, they have to change! There were even some ones who worked here, who beat the children on their back and things! Those lads were expelled, and they found others.

Margarita: How do you think that the future will be for persons with disability?

Amelia: Well; they have to keep on, with vigour. Keep on fighting, so that they can get out well. They must use the power of their own will, so they can go to get an operation, for example. They must keep on actively with their own body, so they might be able to walk, as well.

Tía Amelia emphasises own agency and willpower as way to overcome suffering, and she exemplifies the way with her own history, and that of her sons. She did not turn her affliction into rage, but she followed the typical path of women in Mexico, *the Guadalupe model*, so to say. Her suffering for her children meant struggling, and working, for the family to survive. Her sharing of herself also to the other children is meaningful to her, and reflects her personal values, as well as it bestows her with social recognition. She also actively gives social recognition, especially from her constant participation in *rosarios*; memorial services. Her sons have learnt work ethic from her, and their choices of career reflect the values of their mother, and the centre, where they grew up.

Alejandra - Palapa Papaya as a rescue and a generator for change

Alejandra was a young, attractive woman of 28, and the mother of six young children, of whom the oldest and only girl was disabled. Her husband became disabled as the result of an accident four years earlier. The family is indigenous, from the valley of Oaxaca, and they had come to live at the rehabilitation centre three years ago.

When she was 14 years old, Benito, who was then 25, came to ask for her hand with her parents. They accepted, and from then on Alejandra went to live on the farm of her husband, together with her in-laws. She says that Benito never respected her, he was violent, and often her mother-in-law had to interrupt her son to defend her daughter-in-law. Alejandra became pregnant almost immediately after marriage, and gave birth to Aurora, a girl with Down's syndrome when she was 15. She thinks that Aurora was born *asi* (that way, because her husband had been beating her a lot during her pregnancy. After that she gave birth to a new child, all boys, every second year, until her husband had his accident. He was attacked from behind by an enemy with whom he was disputing a piece of land. Alejandra was then pregnant with her youngest son.

Margarita: How was this really, you married very young, right?

Alejandra: Yes; or he was older than me. I was 14 when I married him, and he was already about 25. Well, as I was little, I didn't know what this meant, really. He came to ask for me with my dad and my mum. They recommended me to accept. And that was it. I married in the civil way, and I went to live with him. After that, a year after, Aurora was there. And every year and a half there was a new little one, and another one. Yes. I had been living about 10 years with him, when he accidented himself.

Margarita: What happened when Aurora was born? I mean; what did you do when she had a Syndrome?

Alejandra: Well, the doctor told us that Aurora has it since birth. Down's syndrome. And it is because of the parents' blood; well that's what people say. That it is the parents' blood, it's identical. That's the reason... But I don't think so, because, well, there are other people who say that when a child is born like that, it is because of beating, or some lack of care. That one was injured during one's pregnancy, and then she was hurt, and that's why she was born like that. Aha. And I think that is true, because when I was pregnant my husband beat me a lot. Aha... He beat me a lot. And I think that; all that beating, that is why Aurora was born like this. With the other children I didn't suffer that much; he didn't beat me a lot, and they were born fine. With Aurora I suffered a lot. I was lifting heavy things, working, lifting, lots of weight.

Margarita: I see. And how were you received with your baby in the village?

Alejandra: Well it is just a *ranchito*, well there is a village, but we are living on a ranch far, far away. It is a single house. Well two houses, with a family, my husband's mother, and him.

Margarita: Did you get along well with your parents in law?

Alejandra: Oh, yes; with my mother in law I got along well. Yes, she loved me, and she was the one telling her son that he shouldn't scold me, because I was a young girl, and he was big, but he, well, as he isn't good in his head; he didn't understand what his mother told him. Then when he had the accident, like seven months later; his mother died. Yes, his mother died; from so much thinking. Yes, that's how it is. Thinking about him, and about me, and well; about the

six children, and how do I manage so that they grow. She was worrying a lot. And afterwards she got ill, and she died. *Ya no pudo*. She couldn't handle more.

Alejandra is explicit about the suffering she went through at the hands of her husband, without going too much into details. The details are not necessary, because everybody knows that he has been beating her, even inside the centre's area: People heard the noise from their hut, and not until employees at the centre took action and told him they could not tolerate this form of family government, he changed. Alejandra's continuous striving for her children to grow up, through working restlessly, is also so visual that tight embroidery would seem superfluous. Nevertheless; Alejandra's account of how her mother-in-law died from preoccupation, serves as substantiation of the hardship they all went through. Alejandra does not seem to consider Benito in respectful ways whatsoever, and she regards him almost as a child. The mutual lack of recognition between the partners must utterly have deteriorated their relationship. What they do have in common, besides their kids, is the language. Both are speaking the same native language, and Alejandra regularly helps broadcast radio-programmes for the centre in Zapoteco. She appears as an open and communicative person, who is also verbose in Spanish, while Benito, who appears more closed, does not seem to engage much in conversations. Together they appear as an illustration of Paz' dichotomy of "open" women versus "closed" men, but while Paz argues that being closed is the desirable state, it serves as protection against the outer world, in my view this argument could as well be turned the other way around. Alejandra's openness towards the world and action is what helps her family survive, and her children thrive.

Margarita: And what about your relatives?

Alejandra: They too. My family worries a lot too; because I've got six children, and how do I manage so that the six children live up?

But, well, as I am here in Palapa for the moment, that is why my father, who is very old, said; "how good that you found a good place, what a relief; where they help you, where they support you." "If you had been another place, no; you would have more hardship." Here they give you food, your monthly pay. I only spend money on the children's studies, and when they need something, their clothes, and their soap. It's not much, since I don't have to buy food.

Margarita: Yes, it's good, but you are also exhausting yourself, because you're working a lot!

Alejandra: Well, yes: I'm working all the time, but if it hadn't been for Palapa... I'm working in the kitchen in Palapa, on the beach; wherever they want me, I go working; washing clothes, cleaning.

I was working 8 months in a restaurant that they call *El Morita*, and from there I went uptown. I was working for a while, like 6 months, I think, with *la señora* Nina, the secretary. Nowadays I'm also working, but it's only washing: Doing the laundry for people. Every week, or every ten days I go to their houses to wash clothes.

Yes, and that is why I tell my husband that there is more work here, and there, were we were living there is no work. Well, there is work, but only fieldwork: Grasping the *machete*, and that kind of work is harder.

Interruption: Somebody is calling on Alejandra from the outside of their hut, and she goes out to see. It is Mari, , who is asking Alejandra to accompany her for a velorio (a vigil) in the neighbourhood, and Alejandra decides to go with her. All right, I say, does she want me to stay to watch her kids? No, that's no problem, Alejandra says. We end the interview and agree to finish tomorrow or another day.

A bit later I hook up with the cooks doña Mari, tia Amelia and Alejandra at the wake. *El Coco*, one of the village's drunkards is being honoured with a vigil in Garp's sister's patio. Garp, who was a friend of the deceased, told me earlier today that he wanted to go to el Coco's vigil, but he is not present. The women tell me Garp can't go to vigils or funerals: it is dangerous for him because of his *llagas* (sores); they can get infected.

(Second recording, a couple of weeks later.)

Margarita: How did you know about this centre?

Alejandra: Well, I got to know about Palapa Papaya on the radio. You know; they are always sending out things on the radio, and as we have a radio, sometimes we listen to the radio. And then another *senor*, as well; he knows this area, and he brought a patient here once: I know that *señor*, and he was the one who told me, that in Palapa Papaya they support persons who need help, therapy.

Margarita: Yes. So you came here because of your husband's need?

Alejandra: Yes, because of my husband. Well, it was because of a wheelchair. As we didn't know where they sell chairs, you see, and they had told us that a chair is very expensive. And as we are poor, we didn't have money to buy a chair that costs 5 or 6 thousand pesos. Aha. And that *señor* told us that in Palapa Papaya they donate chairs as well, or that at least it wouldn't be that expensive. And then the *señor* told me: "Do you want to go?" "I'll bring you to Palapa Papaya, so that you can talk with someone there, to see if they accept you or not."

The family's involvement with Palapa Papaya, had multiple sources. Alejandra had heard about the centre on the radio, but then she could actually go there because she had an acquaintance who knew the centre slightly on beforehand, and who undoubtedly wanted to act as *palanca*, or bridge to enable contact.

Alejandra: So, then I came here, and I spoke here in the office, with a social worker, and she said "it is all right; we will give you the reply soon, first the *señores coordinadores* will come to visit you in your house." "Let's see what answer they will bring you." And within three days they came to my house.

And they told me "yes, it's all right." "We will support you; we see that you need help." Aha. And then... they saw my husband as well; he was really lost, or really bad, with a lot of sores all over.

Yes, he was ready to die. Aha, and they told me that he doesn't need to stay here, let us better take him to a hospital, but let us find something, where could that be? Well, they fought to find a hospital for him in Mexico City, and then they came to fetch him, and they brought him to Mexico.

I kept on living in my house in my ranch for like two or three months, when a friend of me, do you know what he told me? "You need help as well, Alejandra, because of your children." "We can support you with your dispenses (food), but we can't come to visit you daily. It is better if you try to go and live in Palapa Papaya, not least because of Aurora."

And yes! After I told them, they came to get us, and we came here. We had been here for a month when Benito returned from Mexico. They made a room for us, and that's how it happened. That's how I came here. Only for a year,

they told me, but as I don't have my own house (here) yet, I have nowhere else to go, and they told me; "you can stay here for some more time, while you look around for a way to build your own house." Aha, so that's why I'm here still. But now I've got a small spot where to make a house.

It is just passing the old brook. Close to where Cantinflas lives. Well, it's a little terrain, and the house isn't there yet. But I am going to build a house there, and once it is ready, I'll go there.

Margarita: How do you feel the difference between living here and the ranch where you came from?

Alejandra: Well, I prefer to live here. As I have several children, and my husband can't work, well; here there is work for me. All over they need me to work. And in my village there is no work. They don't need one. No, there's no work there.

Alejandra emphasises Aguacatec's favourable position, as a place where she can easily acquire employment. The fact that the site is growing rapidly, not least because of the steady increase of tourism, creates structural advantages for economic improvement for persons who possesses the motivation and ability to exploit these. While the family earlier had lived in an area where land and "Goods" were strictly limited, Alejandra now became aware that here it was not, as it is possible to make a living also beside the limited land plots available.

Margarita: What about Aurora, how was she doing on the ranch?

Alejandra: Well; Aurora was there, and as she didn't know how speak; she didn't know how to do anything. I was helping her: I fed her, I bathed her, and I washed her clothes. I did everything for her. But when we came here to Palapa, they started to give her language therapy, and little by little she is starting to talk. And she is advancing; now she washes her plate, and she is eating by herself. Yes; now Aurora is quite advanced. Now it's only the language. She needs to talk more.

Margarita: Did she go out playing on the ranch, as she does here?

Alejandra: No. No, she didn't go out, as it is a ranch, it's in the mountain, and the children have nowhere to go. It is only forest! There are no villages. The children were only hidden inside the house. But since we came here; wow; my children have become very advanced.

Margarita: And how is Aurora relating to her father?

Alejandra: Well; very little, actually. As he is now, in a wheelchair, Aurora doesn't pay much attention to him, she doesn't obey him. When he goes to where Aurora is, to bring her to bathe her, or to tell her something, she just runs away. She escapes. He can't reach her anymore, because he can't go wherever he wants to in his wheelchair.

Margarita: And how was it before?

Alejandra: Before, well, then Aurora didn't act as that, as then he cared well for her. As she always got ill; he brought her to the doctor. Yes, but now, as he ended up in a wheelchair, he can't follow after her.

Alejandra and Benito's children were thriving in the environment at Palapa Papaya. The boys were usually playing around together, and only little Ernesto (3) was keeping to his mother's skirts. During the day the four eldest boys went to Primary school in the village, and Aurora was usually visiting the different work areas of the centre on her own, and enjoyed acting as a little helper for the permanent

patients. At meal-time she always sought out some of the volunteers, with whom she would eat. Her brothers often sat down in the predominantly men's hut, behind the lavatory, where they visibly enjoyed Garp's company, playing, teasing and singing along to the re-emerging old hit "Yo no fui".

The children's respect for their father seemed to have been grounded in physical dominance, and as Benito now was significantly handicapped, they seemed to escape his authority.

Margarita: I've understood that your own relationship with your husband hasn't been that easy either...

Alejandra: Aha. Since the beginning, since when I married him, our relationship never was so, how to put it; friendly, lovely. There always was a lot of conflict. Well; he towards me, but not me. He always maltreated me.

Margarita: And did he change after his accident?

Alejandra: No. After his accident he remains the same. Always the same! He is very cross, he doesn't have any patience, and then he is very jealous. Yes. That is the problem.

Margarita: And what do you need in order to put up with the situation? Had you ever thought of leaving him earlier?

Alejandra: Yes. Well, earlier I did, sometimes after we had quarrelled, I thought about leaving him; "I better just leave, I leave, alone, well with my children... and he is left alone." But, as earlier I was more... I didn't know anything! I didn't even know a village where to go. That's why I thought it was better to stay with him, because I can't leave the house, and not knowing where to go. And then with the children; where could I bring them?

After we came here to Palapa he remains the same. After his accident I certainly told him "if you can't stand me anymore, it's better if you stay alone." "Or; it's better that you leave alone." "You can find a place where you can stay." You know; as we have several children; they make noise sometimes, or who knows what they are doing, and he; he doesn't have any patience.

Alejandra's relationship to her husband was also taking the form of a struggle, and she chose to give her emotional involvement in her children. Her emphasis of the role as mother over that of wife, was not economically instrumental, but emotionally so. Her undermining of expectations of care for her husband was most of all linked to the fact that she was overloaded by work, though there also seemed to be an element of revenge. As he had mistreated her earlier, and still did, she paid back with indifference.

Margarita: Did you know other children with disabilities before, besides Aurora?

Alejandra: No, none. Earlier, when I lived in my village, I didn't know a single child with disability, other than my Aurora.

Margarita: How did you react when she was born?

Alejandra: Well, when she was born I didn't know that Aurora had this problem. As she was born normal, she was born fine, as a normal child. But afterwards she got sick all the time, and her father brought her to the doctor, to a specialist in Oaxaca. That's when they said that she has got this problem, from birth. That she was born this way. And well she will be like this all her life, she won't get well. And then I realised why she came out *asi*, because many of the children there don't. Well; there is no child there with this problem.

Margarita: I know several children, and grown-ups, with this Syndrome. Yes, and many of them, almost everybody, knows how to speak, well; with a little bit of education. Aurora will be able to speak much more, I think, but for sure; a girl like Aurora needs a lot of attention.

Alejandra: Yes, and I cannot; it is not sufficient to attend her well.

Margarita: Well, but how is she? How did she cope with new persons, like visitors, before?

Alejandra: Well; when she was there, she didn't cope very well with people. No, she didn't; as she didn't know anything, *pues* (well). She just wandered around *así*, half crazy, *así* taking up whatever she found, or eating whatever, which she didn't know what is; if it is edible or not. But when she came here, well they started to teach her. How things are done; what things are edible, and how to greet a person who visits. And she started to learn rapidly! Yes, and after that; wow; she had a lot of friends! She greets whatever visitor who comes by, or whatever volunteer, and then she sticks to them like glue, to everybody.

Alejandra, as primary provider of both material and emotional support for her family, and custodian of their security, was greatly benefited by the institutional and personal relationships established with Palapa Papaya, its users, workers and inhabitants. For Alejandra, Palapa Papaya represented an alternative field of productive relations, where she could securely tread into a more public sphere than before. This included employment, shared childcare, companionship with women and men, and exchange of information, issues in which she took an active part.

She lamented how she had not been able to attend her daughter's needs earlier, and that it was still difficult, but in Palapa Papaya Aurora had changed. Now she was not totally dependent on her mother anymore. She had gained confidence and learnt culturally appropriate ways of behaviour, knowledge, and practical skills. Aurora's development was certainly also dependent of the age she was in (8-9), and her personality, but it seemed clear that her maturity was greatly aided by the change in environment, and all that had contained: In this new environment she responded positively to the new stimuli that she was actively exposed to, for example language classes, a factor both her parents pointed out with satisfaction.

Margarita: In these latest couple of weeks two persons here in the village have died, and I notice that it is the alcohol that causes a lot of problems, for many... How is that in your house?

Alejandra: Well, in my husband's case; he drinks, but not much. And he doesn't get drunk neither, he comes back home tranquil. That is how he is; he doesn't do anything when he drinks. He comes back, and he goes to sleep, tomorrow there's a new day, and he's the same, he's tranquil. And when he comes home drunk, he doesn't reprimand me, and he doesn't beat me. When he is sober he does, but when he's drunk he is very tranquil.

Yes, but sometimes I see the drunkards when they are drunk... I've got a *compadre*; when he drinks he just goes on, he keeps on drinking for three weeks, or 15 days, he's going around smashed every day. Aha. And he arrives like a madman to his house. He scares his children, but well; in my husband's case, he is not like that.

Margarita: That's good. Well, do you know what people from your village think about people with disabilities?

Alejandra: Well: After my husband's accident, people asked me if he would heal. I told them he had healed, but when it comes to walking; he won't walk. Then a lot of people, as they don't know the person to be the same when he results *así*, in a wheelchair, they ask me "why?" "Isn't it possible that he walks again?" "That he becomes like he was before?" I tell them that it isn't, that the doctors tell me that it isn't. He will stay like he is now forever, all his life, *así*. But people think, and they are worried about why? As they don't know people like that, you know. Disabled, who end up in wheelchairs. Sometimes someone from my village comes here, and sees the persons who are in wheelchairs, and they just keep staring. Why? Why are they *así*? Because they don't know, the persons from there don't know any disabled persons.

They get scared, and there are some who are mockers, and they mock a person who is *así*. Aha. Because well; they don't see him. Yes. That's how it is.

Alejandra explained the discrimination persons with disability are met with at the countryside with ignorance. Without saying, she was also illustrating this cultural aspect of poverty while revealing her own unawareness of her daughter Aurora's challenges linked to disability before arriving at Palapa Papaya. Here Aurora was developing new abilities, and her mother expressed delighted pride of all her children's advancements.

(Third recording.)

Margarita: Let's talk a bit about your husband's accident.

Alejandra: Well, when Benito had his accident, he went on an errand to where my father lived, at another ranch. And there, well he had a quandary, with a guy there. And, when he left the place to return home, well, the other guy was hiding, and shot him. He didn't come out in front of him; he hid behind a tree or something, because Benito didn't see him.

Yes, so it was when he didn't notice anything, "and then, the shot rang," he says, and it hit him. And right there he fell, and he couldn't rise himself. Aha, and he just shouted, he says, he shouted, and then as my sister lives close by, she heard, him. And she told my brother in law who was shouting, and they went out searching. And well, then they found him, and then they went home to call for the *topiles* (traditional authority/police).

They told them, and they came and gave him first-help, and they brought him here to Comintla.

Margarita: Good, was it here around, close to Comintla?

Alejandra: No, it was all the way to my village. They found a special car, that came to get him all the way, and he brought him all the way to Comintla, to the hospital. I was at home with my children, when they told me the notice; "do you know what?" "Now they've beaten your husband."

Well, I was scared, and I was also 7 months pregnant. I was frightened, and I had been asking myself why didn't he come back home, it was late. When the notice reached me it was around ten. "Now they have brought him away, you can go to sleep." But I didn't; I left my children, I left my things, my animals, and I went to accompany him. From then on I didn't go back there for about 8 months, and my children were left with my mother. Afterwards I brought him home, and well; that is how his accident was.

Margarita: Who was this enemy, by the way?

Alejandra: Well, earlier he was his friend, but then later on they became enemies. It is because of a terrain, they are quarrelling over a terrain. Yes, that is why they shot him. As he doesn't have brothers, they are only two brothers, and a

sister, and his father died, and later his mother. And those people who hurt him are several, a big family, they are a lot of people; and that is why they beat him. They were going to kill him, but as his day hadn't arrived yet, well, he didn't die, but well; he ended up *asi*.

Margarita: And did he do anything later to revenge himself?

Alejandra: No, until this moment it remains like this. That other guy is living there still. Benito backed out. He didn't even go to report it. He hasn't done anything. That is how it is. One needs to solve some things, but whatever!

Benito's accident was an outcome of social violence, and an illustration of what hides behind national statistics. Typically, this assault was not reported to the authorities, and as such, it does not figure in official statistics. This seemed to be the case for most, if not all, of my informants who were victims of accidents.

Alejandra's response to her husband's accident was first the characteristic of a supportive and devoted wife. In the midst of it all, she gave birth to another child, and after the three of them moved home to their ranch, she did not prioritise her husband, but her children, what she still does. Her husband's response was rage and depression, what the whole family suffered. At Palapa Papaya Alejandra and the children thrived and took much advantage of the new facilities presented for work, communication and education, while Benito seemed intimidated by living so much exposed to strangers as one does in such a place. His family-members relative success and integration into daily practices at the centre seemed difficult for him to tolerate, and he had troubles both coping with his own disability, and encountering other people. His family's achievements, which on one side bestowed him with honour, also seemed to challenge his self-respect.

Irma: I think I would have become a bad woman, if it wasn't for my disability

Irma was also 28 and cook in Palapa Papaya. She has polio sequels, which did not seem to disable her severely. She walks quite readily, but she always uses a brace on her left foot to stabilise and strengthen it. She is married to Abraham, who has got a similar disability as her, and they have two young kids. Irma came to Palapa Papaya prior to her husband. Here she was interned as a patient for some time, and received help, mostly psychological and social.

Irma's story challenges some of the assumptions about motherhood and femininity linked to the *marianismo* ideal, primarily because of her experiences with outward rejection from her mother and grandmother, and secondly because of her temporarily appropriation of the "macho" way of drowning her sorrows in alcohol.

Irma: I come from Taralapa, a bit further from Comintla. I grew up with an aunt. I didn't grow up with my mother. My aunt and uncle lived on a ranch that is quite solitary. So, I stayed with them on the ranch, I hardly went out, because it was very far from my house to the road. I had to walk like from here to Puerto Santo (approx. 5 km), and as I had problems with my legs, I got too exhausted! I got the polio when I was 8 years old. When I got sick they thought that it was something temporary, you know. Later they brought me to the doctor, and I was interned for a period; and that was all; when my temperature was ok I returned home. Afterwards I recuperated and I started to walk, but when I was walking I held myself on to things, because I didn't have strength in the leg. When I was 14 I came to know Palapa.

Then; well my mother sold fruit; papaya, *limón*, and she came by here, and she informed herself, and then I came. But I didn't come with her, I came together with my aunts and with my sister, because my mother did not want to, you know. She didn't have any love for me.

Margarita: Mhm. Why?

Irma: Because she had a husband... or well; she had children with another man, who wasn't my dad, thus she dedicated more time with that *señor*. She didn't want to come with me, she just didn't want to. My sister had to beg her, so that she should come. She paid her ticket; in order for her to come. Then I got to know Palapa, and here they cited me so I could be operated. Thus I went to operate, and I was rehabilitating with therapy and stuff. After I was rehabilitated I went out to work, so I didn't keep on staying here right away.

First I was working in "Acuatecas" (a disco). There with the rags (washing). And afterwards I left, and I returned once again, before I came back to Palapa.

Margarita: And where did you get to know Abraham?

Irma: Oh; Abraham I got to know here in Palapa. I was about 16, I think. He came to do his Social Service, which he had to do in High School. Then he was doing his service, and afterwards he left, and he came back, and...

Margarita: And you made a relationship?

Irma: And we made a relationship. We were engaged for almost a year, and afterwards Marco, our first child came. I got pregnant with Marco, and then; he (Abraham) wanted to stay with me.

Margarita: Did you marry?

Irma: No. *Union libre*. Later, when I started to earn money, I started to save for my terrain. And between the two of us we erected the house.

Margarita: And that was it? It is a story of success. But very tough in the beginning, wasn't it?

Irma: Yes; I struggled a lot, because when I had polio, they depreciated me a lot, my family, my mum, my grandmother, my sister; the oldest one: they didn't talk to me.

They looked at me as if I didn't work anymore, they were ashamed of me. If they saw me on the street; they turned their heads the other way, so they didn't have to talk to me, because they were embarrassed of seeing me, because on that time I didn't use nor sneakers nor sandals on my feet, and you know how the polio always leaves you with one foot smaller than the other?

That was their disgrace. They didn't talk to me. In the street they hid so I shouldn't see them. They ignored me. And the fact that they ignored me was like they were saying that I didn't work anymore, that I was nothing worth in this life anymore! After I came to Palapav Papaya, my mum came here to quarrel with me. When I was sick, she never ever passed by to see me, she hated me, I don't know why.

Irma contrasts her mother's rejection with her aunt's perpetual love. They epitomise the cultural dichotomisation of women, and serves as models for how a mother should and should not be, according to Irma's standards and feelings. Both thus guide her own practice of motherhood.

Irma: My aunt, in comparison; my aunt (was different); I always looked at my aunt as my mother; until this day. And always, after I started working; I always give her a little money, because she made everything in her effort to see me alive, you know. And I got much love from her body, when she embraced me, when she bathed me. She tired herself out, when my mother never did that. Then I keep all this (in my memory). When I gave money to my aunt, and I still help her out, then afterwards my mum started to come, saying that she also wanted some help, and I told her; "when I needed Your help You never gave me anything. The love that You held back... And now You are asking me for money? I won't give You." And she quarrelled a lot with me, she told me that I am a *vaquera*, and that I would have street children, that I would be a single mother...

That I was nothing worth; that I didn't work at all. They called me *rinca*, because I limp, my movements for walking are not perfect. She treated me with the point of her toes. Then; I ignored her as well. I ignored her and I said "You should better go, because I don't want to keep on talking to you!" and in that she wanted to hit me. I told her "You have no right to hit me, because you are not my mother." "Because You didn't raise me; You only brought me to the world." "My mother is she who raised me," I told her, "she gave me love when I needed it, what You gave was not enough for me." And then; she stopped talking to me for like a year, two years. She didn't talk to me, she hid from me, but then after I had given birth to Marco; she came to talk with me. She wanted to talk to me, and see her grandchild. She came to show her interest once again, but that was after that she knew that I had my own house, my home, and everything... Then she kept admiring it, she couldn't believe it, that it was my house. How had I achieved this? She believed Teresa had made my house.

But I told her that "I can prove you that that's not the case". "I have got notes proving that I am the one buying everything." It is everything out of my own effort. And then do you know what is worse? Now I am not treated as the person I was. Now; it is like they show me much more respect than my sisters. Now it is like they give me more importance, because they've discovered that everything they did to me, I ignored it, and I continued ahead. I don't know, but I think I made myself as hard as possible. And I said (to myself); I don't want to fall (prey) for their words, I don't want to give them importance. I struggled a lot, but I didn't end up on the street.

Margarita: And what about other people? How did they treat you?

Irma: Well... the people who don't know; yes (they are excused), because there are also people who yet don't know what a disability is. Still I don't owe them anything, because they kept staring at me, and I told them that if they wanted to know what it was, they should ask me, but that they shouldn't mock. Then they just kept *asi* (like that – staring), and then they wanted to give me help (money), and I told them that I was not one of those who go around asking for help (begging). All that: I rejected it many times. I didn't grab people's help (money), because I could support myself. And that is to have strength and value, because there are people who let themselves dominate quickly, and they grab it.

Irma has strong moral ideals, for herself and others, and criticises disabled people who in her opinion are weak, and let themselves be ruined by begging or accepting money from other people. She makes

clear that non-disabled people who see the disabled as poor and in need of help act dehumanising, an opinion most of my informants seemed to agree about, and articulated in different ways.

Irma: Then later on; with so many ways that my family hurt me; they rejected me, they maltreated me; I was afraid, you know. The first boyfriend I had... He was... he didn't have any problem with his feet, you know; he was normal. But I was afraid of marrying him, that he would reject me later on, because of my disability. He wanted us to marry, but I answered him no, because I wouldn't have that problem once again.

I believe that there falls a grace upon every couple, you know. And I told him better no. And afterwards I found a partner with a disability, just like me. So nor he nor I will have problems. And yes; we do understand each other well.

After her experiences with rejection from her family, Irma did not want to put herself in a vulnerable position, and risk further rejection, and she is happy in companionship with Abraham, where they have become each others constant support.

Margarita: And now; what was the greatest change in your life?

Irma: Well to me, Palapa Papaya was like... they took away the cloth that I had over my eyes. Because in my house, as always in the family, someone major have to *mandar* (decide and make orders), and one has to obey, you know. Thus when they told me that I was a *rinca*, a *coja*, a who-knows-what, because they put so many names on you... then; I felt like I was the only one, and I was almost falling apart. But when I came to Palapa, and I saw many persons with disability, ah; I felt even happy, because I said; well it is not only me. I thought I was the only one in the world, you know. And I looked at Sara and Chico, and I told myself that they are worse off, I can make my own life, I can work, and live better, and I think that that was it: My life changed quite a lot with arriving like that to Palapa. I lost that fright, that shame, because the fright itself creates the shame. I had like a fright, of walking in front of people, or going to a *fiesta*, I didn't go out. And here; there was a foreigner, who took us out, he brought us to the *fiestas*, and that was also something that helped me a lot, personally. I felt that I lost much of the shame, and the fright. And right until now, I feel that I have changed a lot.

Irma incarnates Goffman's claim that "the relationship of the stigmatized individual to the informal community and formal organisations of his own kind is, then, crucial" (Goffman, 1963:52). The relationship to, and observance that there were other people with disabilities, just as her, is the first of three important features that she highlights, which helped her come to terms with her own disability. Secondly, the acknowledgement that there were persons with more severe disabilities than hers encouraged her to trust her own abilities to live independent, and thirdly; the push to go outside the centre's area made her lose shame and fright. Attending *fiestas* is a public place for the exchange of social and personal recognition, and significant arenas for the exercise of "youth culture".

Irma: And when I had my children, my home; it was like wow; I felt the glory. Because; although they are very *desmadrosos* (messy) and things; they completely fill you with happiness. Talking with them, eating with them, what I

never had in my life earlier; we never ate together, and now to have a home, and really united; it makes me think; “wow; this is the life that I longed for.” “It is what I was looking for, and I found it!” And you know; they never reject me. With the disability I have, for them it’s not a problem. I have talked much with them about disability, about their dad’s disability, and about mine. And they understand. And they treat me as to not feeling bad; right in front of people; they embrace me! It is like they say that they don’t ignore you. They are not ashamed of me. Things have changed a great deal.

Margarita: Yes. How good, and you have got some precious children, adorable they are. Really! But listen; you have studied a lot, haven’t you?

Irma: No, only until the second grade of primary school. So, I have not really studied.

Margarita: I’ve been told that you are the only one in the kitchen who knows how to read and write.

Irma: Yes, but it’s just because I studied first and second grade of primary school, but afterwards I still keep practising in books, and so on. And now I do understand better. And I try to help Marco with his homework. I help him with the little that I know.

Margarita: In the last weeks, I have noticed that alcohol makes a great difference in this community.

(Irma: Mm...

Margarita:) There are a lot of people who have got problems with alcohol, and also the murderer was under the influence of alcohol.

Irma: Yes, and well, me too: When my mum came here to quarrel with me, I kept on drinking for several days. I left my job, I was without fixed employment. I started drinking, drinking, and I stayed in the street. Nobody noticed, because I did it on the beach.

But I drank because of the pain in that she treated me bad as a child, she treated me bad as a youngster, and she still wanted to keep on treating me bad. What could I do? Where could I go so that she didn’t... communicate with me? Just seeing her brought problems to me. Where could I escape? But then... You know Rita, don’t you?

Margarita: Mmm, well not personally, but...

Irma: Well as Rita knows sewing, she called upon me to come and learn. She noticed that I was drinking. She asked me what was happening. “What is it?” Then I started to tell her, I said; “I don’t know what to do”, but there I felt a need to; empty myself, because I didn’t know what to do with everything. I didn’t have any girlfriends, because I rejected myself a lot.

I was always going around alone. Thus everything that happened to me got stuck here (*and she touches the side of her heart*). And that was affecting me a lot. Then I started to tell her about my life, and as she saw that it was hard, she listened to me, and she told me; “if you want to, you could go to Oaxaca.” “You could move away from your mum, and so on.” I thanked her, and then, suddenly; my mum stopped coming. She disappeared, as if she loosened up a bit. And that was it. But it seems that Rita had been talking to Teresa; or something like that. (Teresa and Rita are friends, and both are foreigners with influence in the village.)

But yes, it is difficult, having such a life... My sister also complains sometimes, that my mum didn’t give us affection, and all those things; but look at her; she is good! She is good, and still I understand her. I tell her that affection is important, but what I had was worse, “because you are fine, they didn’t despise you,” because they loved her more, because her feet were fine... “Well; just leave those ignorant people,” I told her; “what about me, who they despised in public?” I felt bad! And although I felt bad, they didn’t give me any affection. And then I better kept quiet, because I didn’t have anyone I could tell. Earlier I had anger towards her, I couldn’t speak to her.

Margarita: To your sister?

Irma: To my sister. I couldn't speak to her any more, and Abraham says; "now come on!" "Go to see Chucha!" I say; "what happens is that I can't; I feel a rejection towards her." Still I can't. Well, sometimes I try, I go once a year, or every two years, and she lives in Comintla (20 km away).

To my aunt, who lives as far away as Taralapa I go every month! It's the *carino* (love – affection) that calls on you. And my aunt notices it, because I call her mum.

Irma evaluates her sister's suffering as qualitatively different from her own. It is. Yet it is problematic to evaluate the subjective *feeling* of suffering. "There is no single way to suffer; there is no timeless or spaceless universal shape of suffering" (Kleinman & Kleinman, 1998:2).[\(ikke i ref list\)](#) Irma's sister was also abandoned by their mother, though she did not receive direct mockery as Irma did. At this point Irma can more easily exemplify and verbalise what *she* felt, and she has appropriate arenas where to do it, where she receives understanding and interest, primarily in relation to Palapa Papaya, but also in her own home. "There are communities where suffering is devalued and others where it is endowed with the utmost significance." (ibid.)

Irma: But since my children were born, I feel that peace arrived. The wars from my old life are from before. It is nothing: Now the table smells clean, my house smells clean, and I feel happy. And earlier when I didn't have this work, I felt uncomfortable. But it is because there was no peace in me.

The two of us work in the house, well; I wash, and Abraham helps me hanging up clothes, and washing dishes, and we both rake: One waters and the other one rakes, the other throws the garbage, that is; a united home, with love and affection: communication.

We never fight. From the moment I started to live together with Abraham, which is seven years from now, and six years which we live fixed together, we haven't had any problems. We have never separated, that I come around crying, that he beat me; no; never ever. Some times there is something that he doesn't like; but then he tells me, and that is it; we see that it isn't worth fighting over, because I don't like that.

Margarita: Yes, how good. And did you fall in love?

Irma: Yes... or who knows what happened? It was like we couldn't separate. There was a time, though, that we did, because his mum had problems, she died of cancer. Thus he disappeared for like a couple of months, and he didn't write me, nor call; and I thought that he had forgotten me, just like men use to do: They only get you pregnant, and they disappear. When I was already like six months pregnant, he came around, and he spoke to me. I felt hurt for what he had done to me, you know. He had disappeared in the most difficult moment of pregnancy, the hardest time. But he spoke with me, and he begged me forgive him, and he explained what his problem had been, and he said; "but let's forget about it, I won't let you down!" Then I was like throwing a tantrum and I said; "no, go away, I don't want you anymore!" Although I loved him, I said "no, no". Then he said that he had already waited for a long time; "I am not going away", he said; "I am staying". And that's how he started to stay. I thought he would only wait until Marco was born, and then he would go, but he didn't: I told him that I was going to have Marco with me, and that's how we started.

Margarita: Yes... So you were breaking with the standard of the *machistas*.

Irma: Aha, and a lot of people thought that he would go, because that's what people are accustomed to. What is more; on that time he was a god friend of Israel, and Israel was supposed to be my friend, you know.

Thus I told Israel, and he would talk to Abraham, but I told him “I don’t want you to beg; if he wants to, he must take responsibility, and if he doesn’t want to; he will lose his child”, you see? And then Israel told Abraham; “do you know Abraham; Irma is pregnant!” “Yes”, Abraham says; “she has already told me, and I am happy.” “I will be responsible, I won’t go away”, he said. “What is more, I will take her to the beach tonight to eat, because I am happy that she will make a dad out of me!” And Israel says “are you serious?” “Yes I am serious, I’m telling you!” And everybody was struck, admiring how love just filled us, and I was like; what do I do? What do I do? Am I going, or not? Well he returned, and he assured me that he would not leave me, and that Marco was already his son... And now; he loves them very much. I notice that he stimulates them and... Well thanks God; he became a good father, and he acted like a dad.) There are other men who are *bravos* (angry/proud).

Margarita: Mhm; and what about your own dad?

Irma: I never had one. He went away. He left me in my mum’s womb. I received depreciation right from inside my mum’s womb. When I was in her womb; she rejected me. I pre-sense that, because the love that I received was not love. There is no love. She only talks to me because, according to her, she says that she is my mum, but there’s no love. Because she always says: “No; on top of it all, I got pregnant”, as if she is saying; “what a shame, that I was pregnant!” And she keeps ogling me. Thus, ever since the womb, from she was carrying me; she depreciated me. When I was one and a half years old she abandoned me. Just imagine; a little girl. Bawl, it was really hard for me.

Margarita: Yes. And what about your aunt; did she have other children?

Irma: Yes, she had three boys and two girls. But I liked how my aunt treated us: My aunt never beat me! Never, and this while they are farm people, who sometimes are the people who beat the most... But she didn’t beat me. When she got angry she only spoke very strictly to me.

And when she bought something, she bought the same for all: For her two daughters, and the same for my sister and me. She never treated us as if we were minor than her daughters, no she didn’t. And right until now; she comes here to see me, and now she is old! She is almost like Tito’s mum. Yes, she’s old! Thus, I prefer to go there; because I don’t want her to tear herself out. No, but like when I was in Palapa as a patient; she always came to see me. As she could manage: while my mum never came to see me. She came here to sell, but she didn’t even pass quickly to see me. It was a really hard rejection.

But whatever; now she is paying for it! She has got two sons; well actually I’ve got tree siblings by another father, who are all younger than us sisters, but now the bad thing is that her sons, her favourites; they are behaving very badly towards her. They don’t respect her. They don’t obey her or anything, they don’t give her money; and they go to the disco every night. And she asks “why are my sons treating me like this?” And I am very clear, and I tell her; “do You remember when You depreciated us; supposedly because we were girls? And You said that the boys would be better towards You! Now they are treating you worse! Everything you do to your children will come back to you. What You did not give us, we can’t give You back either. There is no affection, although You want it.”

I tried to help her through one of my sisters once, but she didn’t want to. She lives in Comintla. But she doesn’t like it much there. I tell her to go live with my sister, if she doesn’t want to keep on living there, with those boys, fighting; she says they are fighting; but she refuses to leave, there she will stay.

For Irma her aunt-mother and her biological mother embody cultural stereotypes of the good and the bad mother. Stereotypes and other forms of categorisation are vehicles which help people manoeuvre in their world, they are “good to think with”, to paraphrase Levi-Strauss. The dichotomisation of women, and

especially mothers, is here, as in many parts of the world, a product of patriarchal structures, and as such, it is used by women and men. Irma shares her experiences with others, and thus enforces the cultural model.

In 2005 I had the chance to update myself on Irma's life. She was still working mainly in the kitchen, but she had also started to work outside of the centre, visiting communities where CBR-projects are carried out together with the rehabilitation staff, and accompanying the main *coordinadores* on meetings and conferences in other states.

Margarita: How has disability influenced your life?

Irma: I was 8 years old when I got polio, and I do not think that the disease really affected me much in the beginning. Well, physically it did affect me, but mentally I went on just like before; playing, and even running, but in my own way. I kept on being a child, you know.

In my adolescence I started to get some new problems, because I started to look different at myself. My own family's dismiss and prejudice utterly aggravated my situation.

Nevertheless; I think that I would have become a *mala mujer*, (a bad woman), if it wasn't for my disability. Because without a disability I would not have had the opportunity to know Palapa, for example, which is the place where I began to learn to value myself, because in my aunt's ranch, where I grew up; the woman did not have any worth. As a girl I was used to my uncle beating my aunt, and as mother my aunt was educating her daughters in the same manner, and the daughters with their own daughters: To be weak and fearful and nothing worth. These are values that I do not approve of at all. I believe that they are totally wrong, and the most important thing that I learnt in Palapa Papaya, is to give importance to myself as a woman, as a mother, and as a person with disability.

In these vacations and celebrations of the Days of the Dead I went back to the ranch where I grew up, as I always do. I brought my son and my daughter, who both love to go to their grandmother's place. In the grown-ups' talk these days, almost everybody would tell about personal lives that seemed very difficult. The case was most often that the husband and wife didn't understand each other, and that the husbands beat their wives. I would not enter these discussions much, because I had not much to say. Then the others looked at me, and they told me that I seem so happy, "don't you have any problems?" they wondered, "and why not?" "How is that possible?"

Well, I started to talk, and I told them that it is true; me and my husband we do not fight, we are always busy in our work, and in that way I really appreciate the little time I have got alone with my family, and that we understand each other, and discuss things. Moreover; my husband gives me the chance to develop, and to do my own things. Lately I have started to travel a little bit, to the (CBR) communities, and to conferences, for example. Often I tell my own story, to illustrate how difficult it can be to be a woman with disability on the Mexican countryside. Ultimately we went to Mexico City, and to the city of Puebla, and we were away for almost a week. Abraham approved of my going there, something that is quite rare here, and he stayed and cared for the children. This is something that really makes me content. You know; now it is easier to leave the kids also, because they have grown up a little bit, and they are not so dependent on me anymore, but certainly I have to be with them, and educate them.

Margarita: You seem perhaps a little bit more serious, and able to show your anger more easily than your husband. Is he a little bit softer?

Irma: Yes, that is how it is.

Margarita: What characteristics or qualities have you got as a person?

Irma: I get angry quite easily, when anything wrong happens, and when I get to know about injustice, especially towards women, and towards persons with disability. Actually, quite some people have come to me; women who have been beaten, and persons with disabilities. They have come to me to ask for help, and I have tried to help them in the best way that I can.

And now we have started a new project in my family. We are making rooms for rent, for people who come here, so that as a family we may have another source of income. Everybody says that it is very nice and constructive to work in Palapa Papaya, and I agree; but the money is always a problem, because we do not earn a lot, so in order to maintain the children, and other things, we are very happy to get this other revenue.

Irma's story highlights the weight of *misrecognition* in the shaping of identity. Irma mobilised inner strength as a response to the rejection she experienced from her close family. This might be a reason why she appears more serious than her female colleagues, and her husband. Irma's approach mirrors what Finn Carling pointed out in his autobiography "*And yet we are human*" (1962)⁴⁰. In his childhood Carling had felt a need to be rigid and strict, and he suggests that this might be the (indirect) result of his disability which would be most difficult to overcome. Carling reflects that it is ok to accept some practical assistance when this is offered, not because it is needed, but because it can be seen as a sign of friendliness, which might develop into friendship.

She emphasises her aunts embodied love and care which she *felt* on her body as significant for her own survival and development. Her mother serve as epitome of the bad woman Irma imagines that she would have become herself, had it not been for the encounter with Palapa Papaya and significant others.

On the whole these women's lives highlight the centrality of motherhood in Mexico, and the force of cultural models of identification. As mothers, their strategies for social recognition are drawn from the dichotomous moral ideals of good versus bad women. Due to poverty, taking on paid work is a necessity, in order to provide economically for the family, and especially children's needs. The intense relationship with Palapa Papaya, which provides the families with a tight network, represent an alternative field from where these mothers can engage in productive activities, as paid work and information, while simultaneously caring for their children, and practicing rituals.

40 In chapter 3; *Meeting the Word*.

Chapter VII: Young Women and Self-chosen Strategies

In this short chapter I will treat young women who are not yet mothers, and show how their life strategies do not appear as determined by prior life choices, and cultural models of womanhood, as for the ones in the previous chapter. The women I will present in the following have all encountered Palapa Papaya at a point in their life where they are not primary providers of a family. Because of their situation as students, they have also fewer obligations to work in the daily chores at the centre than other users and inhabitants of the centre. Their situations and approaches related to disability are different. Two are polio-survivors and are using wheelchairs as primary means of locomotion, while two are able-bodied but have a close relative who is disabled.

The young women's stories can be seen as representing different stances towards women's activities, demonstrating that gender roles are dynamic. Their life strategies are at variance with the women treated in the previous chapter, and also with men. As individuals each one is unique, and so also their way of acting in their environment. Therefore the categorisations and generalisations necessary to group some informants together and others not, are somewhat artificial. Still, as I have pointed out previously, categorisations are primarily good to think with.

Dolores: Being injured after an accident is very different from being born asi

Dolores was Tito's daughter, and father and daughter lived together with Dolores' cousin Paloma inside Palapa Papaya. Her cousin Amado, a youngster with severe disability, also lived at the centre, and at some point also the teenagers grandmother. Dolores' and Paloma's stories serve to illustrate some of the variations in gender practices, especially related to age and family status, and to further contextualise Tito's story (chapter 4).

Dolores was 16, and I was interviewing her in the centre's carpentry, where she worked in order to gain some extra pesos.

Dolores: Well, I was living alone with my *abuelita* (grandmother) on her *ranchito* for some time. I was alone for a year, I think; when I was in my third year of Primary School. My dad was living alone, in another place. Then afterwards, my dad started giving a workshop in the nearest village and I moved in with him, and later we came here, to Aguatepec.

Margarita: And when you were a little girl, how did the other children react to your dad?

Dolores: Well, it was good; yes they related very well toward my dad. They liked working with him. And as such, well they related very well, they did not reject him.

Margarita: Aha, how good. The disability might perhaps appear more explicable when it is caused by an accident?

Dolores: Yes, it is very different from being born *asi*.

Margarita: Did you also live together with Paloma and Amado?

Dolores: No, they lived here in Palapa Papaya, they had already come here. It was only my dad and me.

Margarita: I see. And did your mother go to another city?

Dolores: No, my mother lives right there, but not in the same house. She's living with her other husband, that's how it is.

Margarita: Do you keep contact with her?

Dolores: No. Not any more. We don't see her anymore. They separated.

Margarita: Yes. That surprises me a bit; because it seems more normal that the wives stay with their husbands if something like that happen, an accident.

Dolores: Yes. Well, I don't know. They had problems before that, and that's why they separated (*mejor*). My mother wasn't yet 15 when they married.

Margarita: How do you feel here in Palapa?

Dolores: Well; a lot better. Here I've got more opportunities. To study, and I get to know more; and more people. And in comparison on a little ranch you don't get that, because you get to know only relatives.

Dolores' absolute rejection of her mother seems to strengthen Melhuus' indication of the dichotomisation of women, as either good or bad. Melhuus claims that "both men and women have common interests in bad women. Good women need bad women to remain good. ... Men need bad women to remain men." (Melhuus, 1992:213) I agree to these arguments.

Melhuus is treating discourses and actions where women are labelled bad because of infidelity, divorce, or employment, which is regarded as putting a husband's honour in doubt. Moral condemnation of infidelity, and women's lack of responsibility, was also an issue in my setting. In this paper I have paid attention to what seemed most forcefully discussed and sometimes also *felt* by my informants namely "bad" mothers. Melhuus states that "motherhood ... is the central value for women, and being a good mother is tantamount to being a good woman." (ibid: 103). It seemed that women employed these categories extensively, and in a habitual way "needed" them, to make moral sense of their own and others lives. Both for Dolores and Irma (Capter 6), their judgements of their mothers as *bad*, illustrate everything that they do not want to imitate.

For Dolores, her relation to her father Tito is what counts, and her critique of her mother serves to underline this stance.

Paloma: The disabled need affection; like every child needs affection!

Paloma was 15 and lived in a small room in the oldest house in Palapa Papaya, together with her uncle Tito and Dolores. The couple of cousins were always together, laughing, playing and working. Paloma's brother Amado who had a grave brain damage, was interned in the Special Care Section at the centre. The sibling's parents had migrated to the United States, and the children were left to be cared for by relatives. The parents wanted to get Paloma "over there", but it was difficult. She would have to cross the border illegally.

Right now the little family was pleased, because their grandmother had come to visit. She would be living with them temporarily in Palapa. Nonetheless; she was old and seemed fragile, so in fact they would be caring for her.

I had a small bottle of *mezcal* under my bed when I invited Paloma to my room to do an interview. A friend had brought it the other day, as a remedy to put on my belly and head, because I had been feeling bad. To Paloma the bottle brought bad memories, she said, because her dad was an alcoholic. He turned crazy and violent when he drank. When he came home drunk, she went outside to hide the knives, and she pretended to sleep. "My mother also pretended sleeping, but always with something to defend herself next to her." "They fought really bad", she reckoned. Paloma seemed thus to have experienced a somewhat typical pattern of family life on the Mexican countryside, with an aggressive father and a self-sacrificing mother.

Paloma: We lived in a little village that is called Rio Anaconda. It belongs to Cameluca. It is a village where the dialect (Zapoteco) is much spoken. My brother went to stay here in Palapa Papaya when he was two. A neighbour from the village brought him here. Well, my dad wanted something good for him, that he grew up with people who supported him. When my brother came here, my mother was pregnant, and she had me. I was three or four years old when we came here. But we came... my parents came every month to visit him. Then later they brought me here to live.

Margarita: Is it good for Amado here, you think?

Paloma: Yes, it was better that he came here, because my brother has a disability; he couldn't hold his body, not even his fingers, nothing, then here I see that he has improved a lot, with the love of the people, and with therapies.

Margarita: And how was it before, don't you think that the same could have happened in the village?

Paloma: The last time, I don't even want to remember... because my dad, most importantly, he drank a lot of alcohol. And my dad was very violent. He beat my mum, and also he put pressure on me. I don't like to go to my village.

Margarita: So you are also better off here?

Paloma: Not that much, because my mum experienced 16, or 14 years, that my dad was alcoholic. He stopped drinking for 5 years, but he fell into it once again. And that makes me very sad, that he returned to the alcohol.

It's a difficult situation, when one lives with a brother who is disabled, having to help my mum.

Margarita: Yes, and is it only you two?

Paloma: Yes, we are just him and me, and one more; a girl who was two years younger than me. She was also born with a disability; her head was very large, but with water. She died half an hour after she was born.

Margarita: Ah! What luck that you are fine.

Paloma: Yes, yes: Very good.

Margarita: But people in your village; what did they say about Amado?

Paloma: Every time that we brought him to my village, they said he was a monkey. People have a very closed state of mind. I've got some other relatives who are disabled too, but they hid them. Well now it's not that difficult, because now they are exposing a lot about it, that it is normal. But before that, when my brother was *asi*...

Margarita: In Amado it is not that visible.

Paloma: It is not noticeable, but the screaming is. Haven't you heard it?

Margarita: Yes, certainly.

Paloma: People get scared.

Margarita: Yes. And why do you think he was born *asi*?

Paloma: Well, my parents have always told me that he missed oxygen, because my brother needed three days in being born. That is why he got a brain damage. Yes, but people also say that his problem has to be genetic.

Well, first they thought he was a demon, but later; my mother's last name is Aguilar, and my father is Aguilar. Then many persons think that they are related. But it can't be that, I think it was because of lack of oxygen, don't you think?

Paloma has a "commonsensical" explanation for the cause of her brother's disability, based on her mother's bodily experience and memory of his birth, coupled with "professional" knowledge, learned at Palapa Papaya. Folk opinion in their village, however, made a moral judgement, based on beliefs that the parents had committed incest, because they had the same family name. In the village Amado was hence not seen as a human boy, but a devil or a monkey, due to his disability.

Paloma: We lived apart from him first. The reason they brought me here when I was 4, was because they saw that it was convenient that me and my parents were close to Amado, many people divulged in that way.

Margarita: I see. And do you know when your uncle had his accident?

Paloma: No, he was already disabled when I was born. Yes, it's about 15 years ago. And then later he came here, he received support from Palapa, and he stayed with us.

Margarita: And how is it to live here in Palapa, compared to outside?

Paloma: It is very different. Here I live in front of everyone! And I feel that Teresa supports me, but... Some times it can be an advantage, and sometimes a drawback. Taking everything into account: My brother, my parents, everybody.

Margarita: Yes... and for you (*para tí*)?

Paloma: I feel that here I do meet people who can be friends, but it is very different from outside. It is very different.

Margarita: And how do you feel that it is here in Palapa? A bit protected, or?

Paloma: Yes! If you need support, outside it is very difficult to find someone.

Paloma was ambivalent to living in Palapa Papaya. She felt protected, because she could count on support from people there, but she also felt vulnerable, because she was constantly exposed to people.

Margarita: You are left with a great responsibility, I think, although you are not in charge of everything for Amado, not at all, as he gets a lot of support there, in the Special Care Section...

Paloma: But...Marit; I don't think that it is a responsibility, but rather that I need to stay with him. I feel affection for him: I feel that I should stay with him because he is my brother, because he needs me, the disabled need affection; like every child needs affection!

Margarita: Yes, and do you think your life would have been better in the United States, for example?

Paloma: Well, I think that it wouldn't, because it is rather a question of who it hurts. On the other side, I think about my brother's future. Something could happen to my parents, and I need to study something, for my brother's future, and mine. Because my brother will live for a long time, they say. And I need to get my own economic support, to get ahead afterwards.

Margarita: And are you ready to do all that?

Paloma: Yes, yes. For your brother you have to do everything. I have to stay with him for a while, and study; what I like most is studying English To get more ahead! And German. If you don't study, you won't have anything.

Paloma expressed herself through a combination of "traditional" and "modern" ideals. As sister she conveyed a will to suffer for her brother, out of love and commitment. She also wished to keep on studying, claiming this would grant her with the necessary equipment to provide for her brother in the future.

Margarita: And you really like English?

Paloma: Yes, I love it, and that's why I want to learn.

Margarita: Yes, and is it also in order to go to the United States later on?

Paloma: No, no... not precisely for that, but rather because learning English here in Mexico makes it a lot easier to find a job.

Margarita: Your parents called you yesterday, no; they sent you photos, right?

Paloma: Yes, they sent me photos. But other times they call on the telephone also. Some times when I hold the phone for my brother, he screams; he wants to talk, but he can't. My mother, or well my parents always start laughing when they listen to Amado.

Margarita: And what are they doing?

Paloma: My dad works, and my mum works.

Margarita: Are they thinking about coming back?

Paloma: My dad thinks about sending money, and coming back in a year and a half. It was two, but now half a year has gone.

Margarita: Good. Do you have many friends here in Aguatepec?

Paloma: Yes, at least I have got to know many persons here. I am going to the store, and...

Margarita: And do you feel that people here are different (from other villages)?

Paloma: Yes, nobody *te dicen cosas*, tell you things (mock you). But what I don't like is that they sometimes call my brother *pobrecito*, poor thing. That annoys me. Their calling him *pobre* is just the same! It is because he is disabled.

Both Paloma and Amado missed their parents, although they seemed satisfied in Palapa Papaya. As I have commented previously (Chapter 3 and 4), when I was back “in the field” in 2005, Paloma and Dolores had eventually crossed the border and moved in with Paloma’s parents in California. My intuition that Paloma focused on her English classes in order to migrate, might thus seem strengthened.

Frida: Lo hecho ganas⁴¹

Frida’s story further illustrates that female strategies are diverse. Female action is not only grounded in work, motherhood and suffering.

Frida was 24, and a student of Psychology at the University of Oaxaca. Her polio sequels made her prefer a wheelchair for moving around. She was staying in Palapa for about three weeks, during her Christmas holidays. I was eager to get to know her, because I was curious about the experiences of a young woman with disability, as most of the persons with disability at Palapa Papaya were men.

Talking to Frida turned out easy and enjoyable, because she was a great chatter and joker. She was also a reflected woman, who had a lot of thoughts about her own life. She felt lucky to be able to study, and said that she had always done well at school. She has achieved good grades, and thus demonstrated *que lo hecho ganas*, that she dedicates herself. That is also why she keeps on receiving scholarships from Palapa Papaya.

In Oaxaca she was living in a house together with other youngsters, with or without disabilities, who were all connected to Palapa Papaya in different ways. On the purpose of an interview, we entered Frida’s room, in the volunteers’ section of the centre.

Frida: I come from a village in the Southern *sierra* of Oaxaca. Earlier there were no roads there. One had to walk for more or less an hour in order to get to one.

I got polio when I was 3 years old. First my parents carried me to see the nearest doctor, who, noting that I had a fever, said that I was getting a flu. Then they returned home, but after ten days without me getting any better, and without the fever disappearing, they brought me to the nearest city, which was Nisatulco, where a doctor told them that their little girl had polio. I had been vaccinated, but who knows what happened?

Later we went to Oaxaca, where I was in rehabilitation for three years. There they gave me braces; but I didn’t like them; I kept taking them off! Every single time; until my parents decided that I did not have to use them during my childhood. And I had a happy childhood! I was staying outside all the time. My parents were not afraid of showing me, and they carried me to school, if they had the time, or I went on my own, on my knees. That was my only way of getting around until I was 15 years old. I was always doing well at school, and then an older sister invited me to come live in her house, because she had married a fisherman from Puerto Santo.

⁴¹ “I put in my forces.”

Hence I also got in touch with Palapa Papaya for the first time. Someone from Palapa spotted me when I was going to school (Secondary), on my knees, and she started to talk to me, and invited me to come visit Palapa. She also said that with therapy and some operations, I could learn to walk with crutches.

All this happened in a very difficult period of my life, which was puberty. I started to long for a boyfriend, but it didn't seem possible for me. But then with the crutches the boys look at you differently, and even with the (wheel)chair, because one is moving around.

Margarita: I already know that you've had several boyfriends. Have any of them had a disability?

Frida: Well yes; I had one, and it was fun, as if you understand each other better. Be it just some detail; that you want to change a light globe, and you can't reach high enough to do it, and he understands you. Perhaps that was my best relationship ever; I don't know really, because we were very young, we hardly kissed on the mouth.

The other relationships have been with "normal" guys, as we say, which really is strange, because it is difficult for a disabled woman to find a man who is not disabled. For the men it seems easier to find a girlfriend without disability. Almost all my friends have got a partner, but I am like the only one who has got a boyfriend without disability.

Margarita: And why is that, do you think?

Frida: I don't know. Perhaps I am exigent, but I wouldn't like to have a husband with disability. It is a practical problem. I've got several friends who are married and who have children; and it is a lot of extra work. The mum unavoidably has to stay at home, and I don't like that.

Margarita: I also know that you practise sports. How important is that in your life?

Frida: Not so much. I practise sports because I enjoy it, and for my health. There are others who see it differently, for whom it is very important. Many don't have an education, and sport is what fills up their life.

Margarita: And what about the group of friends who join to practise together?

Frida: Well, I go to the (sports) centre because it has everything; gymnasium, running lanes and pool. After practicing I leave; I don't hang around at the centre all day. I don't engage in the gossiping there. Also; a lot of the men there drink a lot.

There are those who are always there. They are very *chismosos*, gossipy, almost as it was like in Palapa earlier. When you talk to one, she tells you things about the other, and when you stay with the other, she tells you things about the first one. That is something that I don't like. Also here in Palapa, I never entered in the quarrelling of the women of the kitchen against those in the laundry, it didn't matter to me. Perhaps that is why I don't have so many friends here. I had a lot of friends here earlier, but they are not here anymore.

Margarita: How did you feel the change to the city (of Oaxaca)?

Frida: Well, that was something that I felt very much, I was almost getting depressed. A couple of times I lost myself in the city. Then the academic level is much higher in the city. I had good grades, but I didn't have much practice.

Margarita: What do you think about the future?

Frida: I want to keep on studying in Mexico City. I will get my Bachelor's, in order to do a Master's.

Margarita: And do you have any special interest?

Frida: Children with learning-problems.

Frida seems to draw on her topic of study, psychology, in her presentation of herself, especially in the short account of her puberty. During childhood she was happy, she asserts, and she explains this primarily to her family's continuous support. Her vacation stay in Palapa is not a refusal of her family, she

explains, but rather a question about practicality, as the whole centre is arranged to facilitate wheelchair users. Several of the young dwellers from Palapa Papaya's "resort" in Oaxaca were visiting the centre during Christmas, and Frida most often kept company with her young friend and roommate Felicia, who was attending high school in Oaxaca. Felicia, who was 16, was also a wheelchair user, due to polio sequels. She was home with her family for Christmas, but as they live in neighbouring Puerto Santo, she was often spending her days in Palapa and Aguatepec.

Karina: In Palapa Papaya I calmed down

Karina was in the beginning of her twenties, and one of the new residents at Palapa Papaya in 2005. Polio sequels were affecting her legs, and she was primarily using a wheelchair for movement, although she was able to walk with crutches.

I use her example to illustrate one of the changes that had taken place internally within the centre in the period in-between my two fieldwork stays. Four of five new long-term residents were girls, and all took part in and helped organise a regional course in *liderazgo*; leadership, for young people with disabilities, which was arranged on a monthly basis at Palapa Papaya. Karina was, however, the most articulated of the ones who can be associated as "a new wave".

Karina was employing some of Frida and Felicia's ways for self-realisation; education and reflexivity. On the surface she had appeared as a successfully integrated person with disability, also in the little town she comes from, but she admitted having struggled with herself to fight the stigmatisation she *felt* from fellows in her hometown. A reason for this, might be that she had applied a quite *militant stance* (Goffman, 1963), but without being able to convey her feelings of being negatively discriminated, other than in subtle ways. Her "militancy" was a demand to be seen as fully human, rather than as a category, but she had not yet come to terms with her own difference, and could not fight that cause alone. Now she was much committed to work for a change of attitude in society in direction of acceptance and inclusion of people with disabilities. This interview took place in the artisan carpentry where a handful of young people were working; fabricating or fixing up toys and other wood works.

Margarita: Karina, you said you wish to help other persons with disability to become independent. Do you think that there should be more places like Palapa Papaya, where they could live like in small protected communities, or is it better that they become independent outside?

Karina: Well, most of all, it is important that their families help them to work with their own disability, you know. Sometimes it is difficult because they lack information. They must get to know what a disability is, because often the family says that he or she is sick, and what they do is protecting them a lot, but that is not how it should be.

Often they don't know what the reference is. And I think that one must work with the local community as well, so that people get knowledge. They must get to know what a disability is, and what a disease is. And then they must support us, most of all to get independent. Moral support, that is: If a person wants to do something special, they should say "yes, I support you", all right?

Karina values personal independence strongly, and sees the tendency of overprotecting children and other people with disabilities as a threat to their development and integration in society. This discrimination, which is not motivated by malice, holds people back. She explains overprotection to be grounded in ignorance and lack of information. It must also be remembered that this ignorance is combined with love, affection, and care. Often parents, and especially mothers, who tend to take most of the responsibilities related to childcare, are overloaded by work tasks, and have little extra time to give special attention, or figure out activities that children or other family members with disability can do. Karina thus believes it is important to involve the whole communities where people with disabilities live, a policy Palapa Papaya employs in increasing degree.

Karina: It is also important that there exists centres as Palapa Papaya, because Palapa helps us to work with disability, and it is the only centre here in the region that work with the family, and not only the person with a disability; in communities where there is no health care centres, for example. It matters a lot that there are centres like Palapa, that work to inform people about disability, because they do a lot of work to get disabled people included in society.

Margarita: And what do you think about Aguatepec?

Karina: Well, it is really quite sensibilised towards disability, the whole society and the village of Aguatepec. You can see it, because in other places, where people do not know anybody with a disability, they get quite surprised when they see one; but here, the times when we have been out in the village, we feel normal, people don't look at us.

Really, they don't even talk to us; we are not taken into account, because people are afraid of talking to a person with a disability (*smiling*).

I think that it is the vision of the village, or the integration of the village that accepts everybody to come in their wheelchairs or whatever, normal and openly, for example in the village festival. But it is all thanks to Palapa, because we need only go to Comintla, or to another village, and people start looking strange at us.

They just keep looking at us, without saying anything; that feels bad enough. Through the support of Palapa we also learn to accept our own disability, more deeply. In my case it was more deeply, at least, because there were certain things that I didn't accept about myself when I came to Palapa, you know; I just couldn't.

Karina compares Aguatepec to her hometown and other communities in the region, and finds that Palapa Papaya's influence must have been substantial in regard to the village's vision and attitude towards people with disabilities. Palapa Papaya seems to have engendered a cumulative effect. Persons with disabilities who now work at the centre, together with others who are highly visible in public life in the community function as role models, both for persons with disability who visit the community or come as temporal patients to Palapa Papaya, their relatives, and other visitors and tourists.

Karina: Apparently I was integrated in society, in school, and everything, but there were also things that I couldn't say openly. That was my problem. I imagine that I accepted myself perhaps 60%, but it was yet very difficult. Yes, I was integrated, but there were things that still hurt me, if somebody asked me a personal question. Actually you could tell with regards to my attitude, because I was very rebellious. Here I calmed down (*smiling*).

Yes, because there were incidents when people asked me things, you see; and I answered them rudely, and I was not able to say what I really felt.

I went to school and everything, but on Saturdays; instead of going out, I stayed at home watching television. It was because there were things that I did not like to confront in society. I went from school to my house, from my house to school, because of the same thing. I did not want to go any further. I had some friends, but only in school. A few times I had to go out to do group works or investigations; then I would arrive in a taxi; work with the others, and then I would leave, and I never said why.

So here in Palapa I was working with that aspect, and I discovered that there are a lot of people with disabilities, and we started to share our stories; "picture that I experienced this and that" and then the others started to listen and everybody started to tell with confidence what was really happening to them. We found we could do that without shame, but then it is totally different outside. Here I can; because here I have received a lot of understanding.

Now I can go outside also, and I am able to cool down.

Karina stresses her personal experience with Palapa Papaya and Aguatepec, as compared to other places. What is crucial for her is the alternative field the centre represents. It opens up a new backstage, where persons can find deep understanding between their fellows, because they have some similar experiences which they can readily use as references in their discourses. These are experiences linked to own bodily limitedness, other people's responses to this, and cultural attitudes and beliefs. Earlier, in their communities and for some also in their families, they have silently accepted what they have *felt* as discrimination. They might have been reluctant to mingle with other persons with visible disabilities out of fear that this would further stigmatise them, as for example Abraham told about (Chapter 5). What is equally important, and perhaps more difficult to attain, is the front stage that Palapa Papaya affords. Here they can make common proposals towards authorities of different kinds and initiate activities. Important for the fulfilment of their front stage activities, is the supportive backstage, where they can make plans and express doubts.

Karina and her young companions in "the new wave", that is the little group of five who are new long-term dwellers at the centre and the other 20 participants in the leadership course, are emotionally committed and engaged, they have faith (or *illucio*) in the game they play. This makes them effective "politicians" for their sake, namely influencing local attitudes towards persons with disability.

Karina: My attitude became my problem, because if somebody was looking at me, I would say; "hey; what are you staring at?" or I would say; "hey; is something happening?" because they kept watching me strangely. When I was going

out to work and things, if people were looking at me on the bus, I would say; "hello! How are you doing?" but it was all in an annoyed voice, I did not say it out of pleasure, you know.

It was something about the situation; I was much annoyed. Like; "what's up, huh?" (*making an ugly face*).

Margarita: But you had some reason too, hadn't you? Though I imagine it was probably a very aching way of making a statement, for you.

Karina, laughing: Yes, but I got used to that way of being. Sometimes I also had cross experiences at school, for example of ignorance, or I felt that someone only talked to me when they needed my help, you know. And when they didn't need me, I was nothing; they said "hello" to me, and that was all. But if they needed some school material or things like that, I was a possible rescue, because I was a much applied girl, you know.

I was very punctual, and I brought everything that I needed. And sometimes the other students said "lend me, or give me, some ten pages", but they spoke to me in a way that I didn't like, not like a companion, and as I was one of those persons who was easily annoyed, I would answer "why should I, if you don't know me?", or simply "no, I haven't got any". I was really bad in that, but it was not because I wanted to be bad. It was how I felt like, and not being friendly was like revenge for me.

Or, for example; I was studying in a school where I took secretary work as a material, but I had already studied computers, and the secretary course was with computers' work. Since I had already studied that, it was like a piece of cake, for me, you know. And actually I acted very selfish, but it was due to the same thing, and that was my attitude. Because of the rejection I felt, because some only spoke to me when they were forced to, and nothing else, if I saw them on the street, they didn't even say hello. I thought that it might be because they felt ashamed of knowing me, and I said to myself; "now, they are going to pay for this at school, because they will need me." Always when they said; "listen, can you help me with this?" I would say "no, I don't know you", or just "I can't", but it was due to my rage, most of all.

Nowadays I laugh when I think about it, but it was perhaps a way to liberate my anger, I think, and hope, because I had always a lot of confrontations at school.

Well, now that is over! But there are some who live through this today as well, the youngsters who study are going through this over and over again. It is still happening in the schools here around. Now I go around sharing my experiences, I tell people how it feels; for example what happened a lot in high school; in the most difficult classes: What counted a lot there was to go forward and do an example on the blackboard, or when the teacher dictated a case in Maths, English, or Chemistry; only the first five to hand in their notebook got credits.

And it is logical that I got behind, even if I finished the examples, because in the moment that everybody started to jump and run around the classroom to hand in their notebook, I was left behind.

It surely was unfair, and I even told the teachers in the situation; that I had also finished; "look, I finished as well, professor, but now the five books are already in, so what can I do?"

I believe that things like that are still very common in the schools, actually I just heard about a similar case with Aurelio (who is blind), in the school in Comintla.

With Aurelio it is exactly the same thing as what I lived through. He came one day and said "imagine; I did not receive participation at school, because of this and that". And then I told him that I had experienced exactly the same thing when I was studying, "but let us go to your school and make a workshop, and comment it!" "And while I comment my experience, the theme will brake through, little by little", and luckily that is what happened.

We went there to do the workshop, I commented on my own experience, and how it felt when my companions finished their work, and I did as well, but then I couldn't hand it in fast enough. That was unjust the students agreed, and that is where the theme opened up, and they had the opportunity to talk about what was really happening in their school.

"What is happening in this school, also happened to me," I told them, and the example of a lived experience is often powerful, you know.

Karina is highly reflexive about her own situation and history, and much committed to work for disabled people's sake. Her reflexivity is a feature that she seems to have further developed during her stay in Palapa Papaya. She readily analyses and gives explanations to her own previous behaviour and attitude. Her feeling of not being recognised as a companion, as a human being while in school, motivated her trying to revenge herself by not lending favours to her schoolmates. Her suffering was turned into verbal rage, but she could only articulate this in cross terms. This did not solve her troubles, but rather cast her into a negative spiral with regards to social relationships. However, it seems like the tough attitude she employed during her school years, somewhat protected her self-worth.

Now, through the protected space and time in Palapa Papaya, she has been able to recast her own life situation and way of acting. From a base where her humanity is fully recognised and appreciated, she has turned into a woman who *gives* recognition, who confronts challenges, and who initiates social actions, as the workshop in Aurelio's school, where she was able to convey a message of injustice in a way that made students comprehend, without offending them.

Margarita: A propos examples: Have you got any idols?

Karina: With disability?

Margarita: For example.

Karina: Oh yes, you bet, I have; a lot of them! For example Saul Mendoza, who is the paralympic competitor who won in Athens 2004 (Wheelchair racing). I swear that he is my biggest idol! I saw him on television, and it was like WOW – I would like to get to know you! But it was also a little bit annoying at home, because always when there were sportsmen or other persons with disabilities, my family was like; "look, do you see that Karina?" I only liked Saul Mendoza, and well, I have this obsession with Saul Mendoza, and then we had the opportunity to get to know him personally, in Nisatulco!!!

Yes, we were the first ones to file up, isn't that true, Laura? (*Karina asks Laura, who has been dedicated to her work, painting a wooden parrot.*)

Laura, smiling: Yes, that is right; filing up to talk with Saul Mendoza.

Karina: We also met Alfonso, and Juan Ignacio, the one who came third in swimming. I don't really know where Juan Ignacio comes from, but I think he is from Mexico (City). He doesn't have any arms.

To be honest, I didn't know him, but I wanted to see him as well, because I had been watching the Paralympics from Athens 2004 passionately, wow – let's go Mexico! And I desired to see them, but how could that ever be possible? Then; through Palapa my dream of getting to meet them became true. I also met Patricia - I don't remember what discipline she won; all the sport competitors with disabilities!

And they are my idols, you know! Because they are showing that it is possible, and to me it is like an example to follow. Also when we took a course in Human Development here in Palapa; I got much motivated, to keep on forward. What surprised me was that all the ones coming to give classes were persons with disabilities! And really; that helped me

a lot, because take Vicente, for example. He was the first one to hold a class, and it was such a great theme; “how can he do that when he is blind?” I thought. But he did such a nice job, wonderful, “why can’t I do that?” I said to myself; “if Vicente needs a little bit more help than I do!” It was like I started to inject myself with energy! And after that; new lecturers came, and I felt that it was a better one each day.

Then I said “ok, enough is enough.” “What is happening to me?” I decided to try a little bit more, and then I got even more decided.

As I just mentioned; I was accustomed to go from school and right home, and I didn’t know how to enjoy life. I never went to a disco, or anything else.

Margarita: And did you do any sports?

Karina: No, it was always from school and back home, from school and back home, but when I arrived here, after a while Vicente and all the others said; “come on – lets go out to eat!” and when I actually went out, I found it was great, and also it was together with other persons with disabilities, and we had plenty of things to talk about. It was just great, and it was through Palapa that I got to know these people, with whom I still stay in touch, and to me they are very important persons, because they represent great living examples for me to follow.

And I want to keep on moving forward. There was another person as well; Marco Antonio, who came to give his section, and who made me feel like “wow – these are my idols, and I would like to be as them!” Not to replicate them, but to learn from their examples. I want to feel realized, and do what I want to do, that’s what I have dreamt about always, but I did not have the courage to go for it.

For Karina, the existence of role-models with disability is important, both distant ones, like famous sports stars, and closer ones, like the ones visiting Palapa Papaya to lead workshops. Her friend Laura also pointed to workers and inhabitants at the centre as *her* personal role models

However, these women do not seem to draw as much on cultural models of womanhood as the mothers presented in the previous chapter. Still, the dichotomisation of women into morally good and bad is a feature that guides their own formation as women, and especially what they do *not* want to become. It is plausible that they might live more up to traditional cultural expectations when or if they become mothers, but they will be better equipped to see and explore alternative opportunities, as a result of their formal education, and their affiliation with Palapa Papaya. These qualities and connections will serve as *palancas* in their further development. Many of them still relate to a marianismo ideal, but they might come to employ the Virgin of Guadalupe more as a symbol for political empowerment, than as a model for suffering.

The young women, taken together, indicate that quite a change is going on in Mexican culture and society. They are expanding the concept of womanhood, employing opportunities that are open to them, in regards to education and formation.

Chapter VIII: Conclusions

The crucial feature of life is its fundamentally dialogical character. (Taylor, 1994:32).

Through an insight into the life-worlds of people with disabilities and their significant others (Mead, 1934) I claim that one can become more aware of the importance of social recognition, respect and dignity. This need is panhuman, but the forms it takes are culturally and historically patterned. The struggle for recognition therefore needs to be understood in its own socio-cultural and economic context. As a contribution to this general discussion in anthropology (and social science per se), it has been an aim of this thesis to present and describe how such struggles took place in a little village in Mexico.

I adhere to the theory that “our identity is partly shaped by recognition or its absence, often by the *mis*recognition of others” (Taylor 1994:25). Disabled peoples’ collective demands for recognition, articulated by pressure groups and organisations, are often shaped as a politics of “multiculturalism”, in the same vein as political feminism, blacks’ movements and ethnic minority groups’ claims. Such demands and a discourse about “rights” are also formed and supported by Palapa Papaya, the rehabilitation centre where I undertook my research.

Charles Taylor explains how, as a further historic development of the idea of personal authenticity, “the importance of recognition is now universally acknowledged in one form or another; on an intimate plane, we are all aware of how identity can be formed or malformed through the course of our contact with significant others.” (Taylor, 1994:36)

I focus primarily on this intimate level, and following the Kleinmans (1991), I wanted to find out what was *at stake* for my informants and friends, and use this as a point of departure. What was, and had been, decisive in their shaping of their own identities?

Participatory observation is in its character dialogical. By spending time with and showing interest for others’ lives and practices, one *is* giving social recognition. The empiric examples that I use in this work, are largely personal narratives presented in conversations between informants and me. I have chosen to let people’s own presentations be in focus, adding more information and analysis in order to reveal motivations and clarify pictures. An attempt to contribute to a “humanizing ethnography”, has been an important concern for me, both during fieldwork and in the process of writing a final paper.

Describing the arrangements at the rehabilitation centre Palapa Papaya was important in order to expose the circumstances under which the persons treated in this thesis lived and acted. In an environment of poverty, Palapa Papaya and the village of Aguatepec represented an oasis of opportunities in which to overcome material scarcity and lack of information about health and social justice. Daily life was characterised by work, and in the interaction between workers and users of the centre stereotypical roles were embraced, challenged and changed.

Gender roles have often been conceptualised as prisons. Though, for some persons with disabilities, the constraints imposed by a gender ideology, as machismo/marianismo, seemed to come out as liberating or even empowering, a freedom from the category as disabled.

For all my informants it seemed significant to be recognised as men and women, mothers and fathers. This was an attractive identity aspect. As one informant put it; "I am a man and I will keep on being a man all my life!" Implied in this statement is the assumption that being categorised as man, or woman, is paramount, and much more esteemed, than the categorisation as disabled.

For women who have children, embracing a role as self-sacrificing mother, gave them crucial social recognition, particularly within the centre. In order to gain recognition outside the centre, they still needed to enlarge their social circles, and involve themselves in other culturally approved practices, as work and rituals, particularly memorial services.

For men, risk-taking seemed to represent a habitual and expected way to prove manhood, and gain or increase recognition from others. Many engaged in a somewhat aggressive quest for respect, and this cultural feature influenced the proportion of certain disabilities, primarily spinal injury. An indication that risk-taking was loaded with meaning and worth was the maintenance of risk-taking also among men who had acquired disability. For some of these men embracing and exaggerating an aggressive ideal of machismo seemed to be their way out of a stigmatised category as disabled. I perceive heavy drinking and substance abuse also as a somewhat aggressive mode of risk taking, as it in its competitive manifestations often was accompanied by verbal insults and violence.

Alternative, non-aggressive strategies of risk-taking were also employed, particularly by men. Involvement in sports and life-guarding at the beach were such activities, which in a dialectical relation generated social and individual recognition, through admiration of the actors, and enhanced self-esteem.

As articulated by Lancaster (1992) machismo can be seen as a *field of productive relations*. I observed that men in my field setting were not only taking risks in order to realise themselves as men. Other alternative strategies were also employed, as that of family provider, church leader or business man.

Machismo, as other ideologies of power and submission is frequently challenged and changed, by individual actors who serve as role-models for others, and by organisations and social movements, here illustrated by Palapa Papaya. To bridge the gap between organisations and individuals, facilitating their influence on each other, persons who work in organisations are important, both as messengers and role-models out, and as *palancas*, beneficial mediators, in to the organisation and out to its further network. I conceive of all my informants as embodying these functions, but the men presented in chapter 5 seemed most consciously aware of their double role. These persons were embracing another end of the machismo contour, broadening its scope by their living examples.

The women I have portrayed in chapter 6 emphasise their struggles to overcome hardship, and they are explicit in their praise of Palapa Papaya as the place to rescue themselves and their family from poverty and discrimination. Their daily activities are filled with practical work and care for family members. Although they often talk about this work in a language of *suffering*, this kind of suffering is perceived as a light burden, often contrasted to the adversities they had faced before encountering Palapa Papaya. I have focused on how their work is codified in a language of suffering, which in itself exists as a meaningful female virtue (Melhuus, 1992:162), and how they consequently receive social recognition from their co-workers and fellow villagers.

The young women portrayed in chapter 7 differ from the older ones in that they do not experience or discuss suffering as a primary condition in their life. As one said; "I want to feel realized, and do what I want to do. That's what I have dreamt about always, but [earlier] I did not have the courage to go for it." Through the encounter with Palapa Papaya, she and other women gained a secure place, where their lives and feelings had *resonance* with others' (Wikan, 1993:190), where they were encouraged, and encouraged each other to work collectively and individually to attain their dreams. They found and shaped opportunities where they could learn about and work to promote the [human] rights of people with disability. They are well equipped to grasp these opportunities, due to their personal experiences related to disability, and their education. However, the fact that they were not yet mothers was perhaps the most significant aspect which liberated their time and work capacity.

For men and women alike, engagement with the society outside Palapa Papaya is important for their social recognition in the village.

Particularly for women participation in memorial services (*rosarios*) seems meaningful, as a place where mutual public recognition is exchanged between the women, relatives of the deceased, and other participants and mourners. Watching *telenovelas* is also a popular female activity, and most often this takes on highly social forms. The ones who dispose of a TV-set, will often watch *la novela* together with their children, *comadres* (intimate friends) or neighbours, and the ones who do not have this luxury item, have a legitimate reason to visit female friends. In both type of event much additional information is exchanged, and both this type of information (gossip) and the content of the events themselves represent substance for daily discourse among women.

For men the arenas of drinking (*cantinas or bars*) and sports, either as participants or spectators, are important fields of interaction. Relations in these arenas are by and large friendly and playful, but when competitive aspects are mixed with existent rivalry, aggression will often arise, leading to quarrels and fights. Thus, for men in particular, the environment offered at Palapa Papaya represents an alternative field, where to rehearse different gender roles in interaction with women and men.

Practice show that machismo and marianismo, seen as gender ideologies, are not static, but flexible and changing, which is shown in this paper. Lancaster wrote that machismo can be seen as a *field of productive relations*, and I will argue that the same is true for marianismo. As interdependent ideologies, they are both flexible and changing, historically and situational, which this thesis bears testimony to.

Palapa Papaya represents in itself a community within the larger community of Aguatepec. Both communities are based on democratic principles and they have a relatively short history, in which they seem to have influenced each other increasingly. More people with disabilities have settled in the village and in the region, plausibly as a result both of the location of the centre there, and the changing and more tolerant attitudes people with disabilities meet in the village, what is creating a generative effect.

For people with disabilities, their disability often becomes an imperative status, and they are classified as 'disabled'. In this thesis I have shown how much agency and creativity, strength and courage it takes for a disabled person to gain recognition with a variety of statuses, as a man, woman, husband, daughter, an Irma an a Garp. It has also been important to show the significance of a level playing field like Palapa Papaya in order for processes of recognition to be enabled.

The centre itself has increasingly come to represent something like a feminist stronghold locally. It was founded by a man, but when he unexpectedly died his close female companion took over the responsibility of the newly founded centre. She has been able to manage and expand the centre in many ways. In vein with international political and policy trends, Palapa Papaya has come to emphasise human rights, and its derivatives; women's, children's, and most vitally disabled people's rights.

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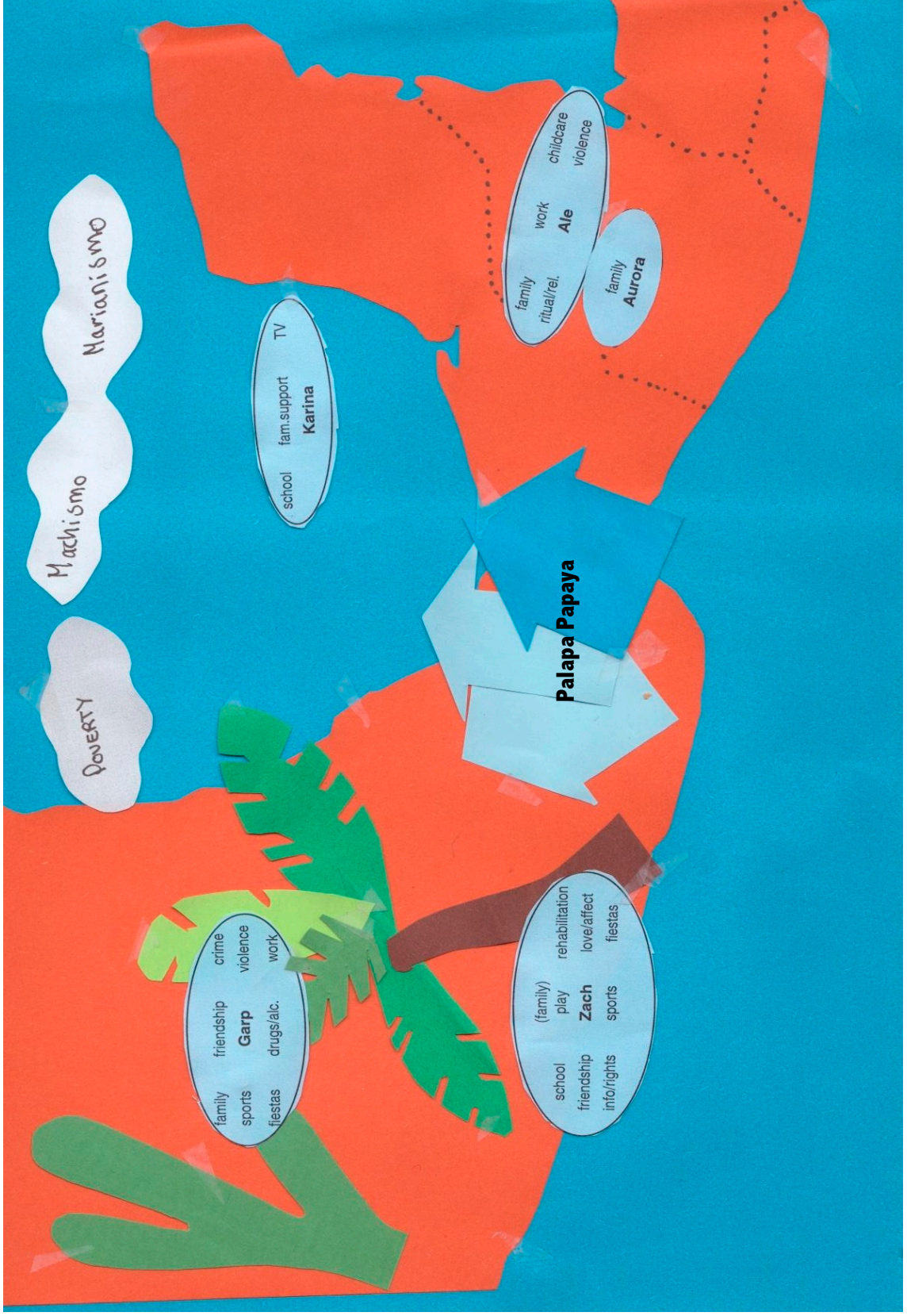
<http://www.inegi.gob.mx/inegi/>

Appendix 1: Model

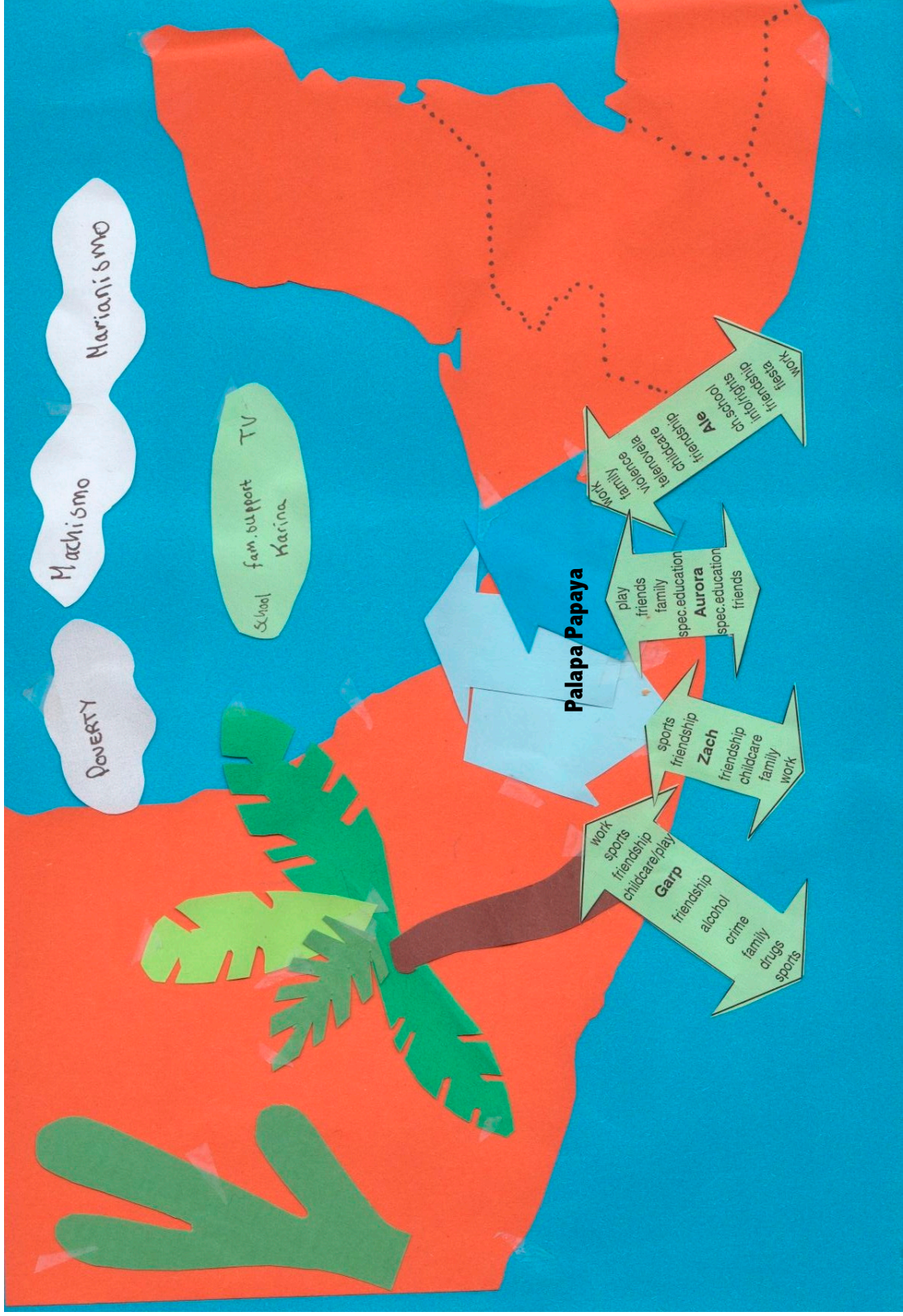
The following model is an attempt at bringing together some of the threads that I have located throughout my study. The words associated to each person connote their strategies for living and gaining social recognition. The three versions of the model illustrates how actors' affiliation with the rehabilitation centre Palapa Papaya changes over time, and how it seems to influence individual's activities, and hence life-worlds.

The three clouds represent structural and ideological constraints.

1. Example of actors' social activities prior to attachment with Palapa Papaya.



2. Example of actors' social activities during my fieldwork at Palapa Papaya.



3. Example of actors' social activities in November 2005.



Appendix 2: Pictures



Adding to the ofrenda, note the Virgin of Guadalupe in the background.



Inside the memorial chapel.



Paths inside Palapa Papaya.



Artisan at work.



Hanging out outside the kitchen in Palapa Papaya



In 2005, access to the beach had been facilitated



Artisan.



Playing basketball

Appendix 3: Black and White Pictures.



Palm tree climbing.



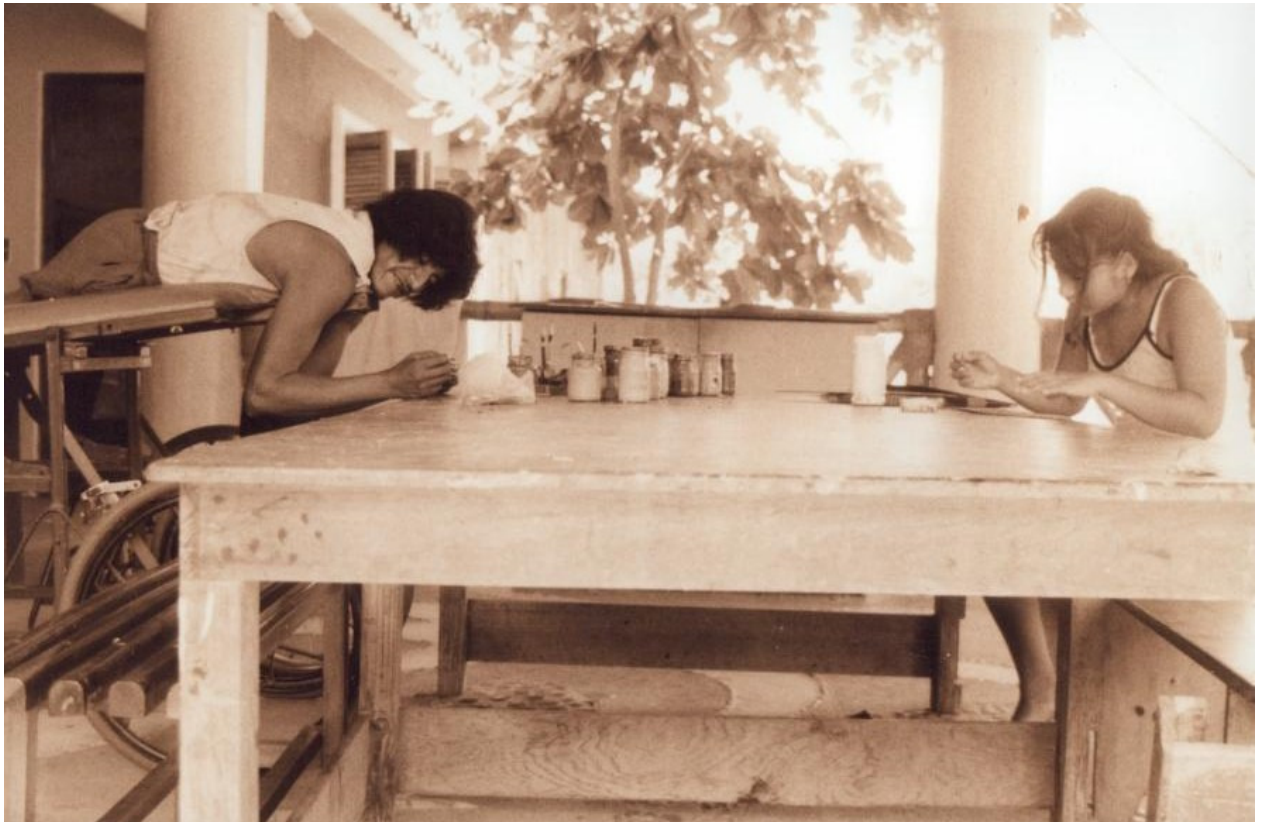
Waiting outside the kitchen of Palapa Papaya.



Children collaborating at Palapa Papaya.



Eating inside the *comedor* in Palapa Papaya.



Artisans working.



Volunteers' hammock workshop.



Playing in the *comedor* of Palapa Papaya..



Working out in Aguatepec.



Playing basketball in *la cancha* in Aguatepec.