

**Being parents/guardians of disabled children
in a low income area in rural Mexico**

A qualitative interview study

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Abbreviations

AIDS	Acquired immune deficiency syndrome
CBR	Community Based Rehabilitation
DIF	Desarrollo Integral Familiar (Integrated Family Development.)
ILO	Independent living organization
INEGI	Instituto Nacional de Estadísticas de Geografía e Información (National Institution of Statistics on Geography and Information)
MDRI	Mental Disability Rights International.
PHC	Primary Health Care
TBA	Traditional Birth Attendant
UD	Utrikesdepartementet
UNESCO	United Nations Educational Scientific Organization
WHO	World Health Organization

Abstract

This qualitative study aims to describe parents/guardians perceptions of living with disabled children in rural Oaxaca, Mexico and their feelings about living with the disabled children. Fifteen semi-constructed in depths interviews were conducted. Qualitative content analysis was used to analyse the transcribed interviews. The informants came from thirteen different settings. All were part of a rehabilitation program. Results showed that parents/guardians faced many challenges. There was little knowledge about disability issues. Poverty, lack of insurances and traditional beliefs impeded access to health, specialists, rehabilitation and schools. Society failed to meet their needs. Stigmatization was common. Children were hidden at home. There was no parents' organization. A local rehabilitation worker would facilitate rehabilitation and integration. Children could be detected earlier. Parents/guardians couldn't take on this role. They had to work to maintain their families. They needed support from the authorities. Disabled children should be targeted in mainstream programs for health and development. Primary health care professionals need more knowledge and judgemental attitudes must be avoided. Social security for all citizens is urgent.

1. Introduction

Why are so few persons with disabilities and their families participating as advocates in their communities in order to improve their life conditions? And why is there a lack of local rehabilitation promoters in most Community Based Rehabilitation (CBR) programs?

The number of disabled people in the world is increasing. Ten percentage of the world's population have a disability, and 10% of the worlds children are born with or acquire a disability. Of these children less than 10% will receive rehabilitation. These figures are including reversible conditions like mal-nutrition, wars and natural disasters (WCPT 2003).

International policy on disability

Protection of human rights of individuals and social inclusion of disabled people are embedded in international legislation and policy. Health promotion, prevention, rehabilitation, social integration and equalization of opportunities for people with disability have been the policy for WHO and UN for many years. The focus has been on Primary Health Care (PHC) and Community Based Rehabilitation (CBR). The importance of the participation of people with disabilities, their families, carers and communities has been emphasised (WCPT 2003).

Community-Based Rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of the disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services (ILO, UNESCO & WHO 2004).

CBR promotes the rights for people with disabilities to live in and fully participate in all activities in their communities. CBR requires that governments transfer responsibility and resources to the communities, so they can provide the rehabilitation needed. This includes support to community members to enable them to participate actively in the CBR-program, and support for treatment, education or equipment to those with special needs, which is not available at the local level. Lack of community workers is a problem in most CBR-programs (ILO, UNESCO & WHO 2004).

2. Background

Mexico's population is estimated to be 105 million people. 12, 7 millions are indigenous people, who still live in Indian societies and speak their native languages. Oaxaca is one of the poorest states in the country and has a high percentage of indigenous people. Many indigenous communities are still maintaining their cultural worth and values, while trying to integrate themselves economically in society. They are target to profound discrimination and marginalization. Nine million indigenous people live under the poverty line (UD 2004).

Collecting data about disability is quite new, and there is a socio-cultural problem connected to recognising and admitting that a person or a family member has a disability. In the year 2000, 2.35% of the total population had a disability, and 6.35% of the children enrolled at school were disabled. In the group 0-14 years of age the most common problems were mental disabilities and mobility impairments. They were associated with birth, the perinatal period and congenital factors. (INEGI 2004).

Government Action on Disability Policy

Mexico's government is implementing the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Michailakis 1997). The political constitution includes equal opportunities, free basic education, health protection, equality between men and women, right to justice and work, decent housing and protection of minors. Persons with disabilities are guaranteed health and medical care, rehabilitation and counselling, financial security, employment, independent living and participation in decisions affecting them. There are laws about accessibility in the environment promoted by the local and national governments (Michailakis 1997). There is still a gap between laws and reality. In the capital it is unusual to see persons with mobility impairment. Infrastructure and public transports are not adapted to their needs (UD 2004). People with disabilities participate to a very limited extent in Government, legislature, judicial authorities and political parties, and to a great extent in NGO:s (Michailakis 1997).

Disability and Mexico's Health and Educational System

Mexico's health expenditures are 6.6% of BNP. Half the population is uncovered by health insurances and the out-of-pocket payment is 52%. In spite of new health and social reforms people who lack insurances have little or no access to adequate health, treatment or rehabilitation. The wealthy part of the population uses the private health system which has high standard (UD 2004). Ninety-two percentage of the population with a disability use the health system, but only 45% are covered by social security. Geographical differences are prominent. In the state of Oaxaca 23, 4% of the total population is covered, which is the lowest figure in the country (INEGI 2004). The national health system is too expensive for the poor, marginalized people. Quality of care is low, and complains about service providers' behaviour and mal-practice are frequent (Tamez, Molina 2003).

Compulsory school attendance is nine years. There are big regional differences between urban and rural areas and between the north and the south. In some states less than 60% of the students finish primary and secondary school and 1,7 million children don't go to school at all. Poverty forces them to start working. Wealthy families choose private schools for their children to a great extent (UD 2004). The average time that disabled children spend at school is 3.8 years (INEGI 2004).

Disability and Culture

"...disability is defined by culture, and without an awareness of how disability is perceived in the target culture, a disability programme does not stand much chance of being relevant and sustainable."(Coleridge 2000, page 21 referred to by WCPT 2003).

Although CBR-programs focus on the community level, many development agencies and national governments assume that disability-beliefs will move from traditional attitudes and practice to a western based charity or medical model, which would further disempowered the individuals concerned. People do not abandon old knowledge and practice and just accept new systems. Often old and new belief-systems are mixed or co-exist (Groce 2001).

Disability, Poverty and HIV / AIDS

According to Lewis (1961) "the culture of poverty" is a way of living, and it is different from just being poor. A poverty-culture is created when the old social and economical society breaks down and is replaced by another system. Transition from a feudal to a capitalistic system, times of fast technological changes and wars are situations which can create cultures of poverty. Absence of participation and feelings of not belonging in society are common. The level of education is low, unemployment is high and the people are marginalized and discriminated. Most people who live in a culture of poverty do not belong to trade-unions or political parties. They are suspicious towards governments, the police and authorities. On the local level there are wretched, overcrowded houses, and a minimum of organization outside the family. Childhood as a protected part of life is absent; and there is a high degree of abandoned mothers with children. The women become head of the household and education forms are authoritarian. The individual has strong feelings of rejection, helplessness and inferiority. He or she is not class-conscious, but very sensitive to differences in status. He/she is aware of his/hers problems and local conditions but have little knowledge of history. When the person becomes class-conscious or a member of a trade-union or acquire an international view of the world he/she is no longer part of the culture of poverty, though he/she might still be terribly poor. Basic changes in attitudes and value systems must go hand in hand with improvements in the material conditions of living to eliminate the culture of poverty (Lewis 1961).

In Mexico the estimated number of people living with HIV / AIDS were 150 000, and children orphaned by AIDS were 27 000 (UNICEF 2003). Persons with disabilities in Zimbabwe had not been targeted in the mainstream HIV/AIDS prevention. AIDS-service organizations did not consider disability their issue. People with disabilities did not seek help, because of inaccessibility to buildings and structures used by service providers. The attitudes of the service-providers also influenced the help seeking behaviour. There was a high level of discrimination and stigmatization by the community, but disabled people also stigmatized each other (Banda 2002).

Disability and stigma

There are three types of stigma according to Goffman (1963). First there is a physical stigma that is obvious to everybody, for example a blind, deaf or mobility impaired person. Secondly there are spots on the persons character associated with weakness. The person has been in a psychiatric hospital or jail; he/she is unemployed, an alcoholic, homosexual or has a disabled member in the family. These stigmas are not always visible. Thirdly there are stigmas that are inherited from generation to generation like tribe, nationality or religion. Goffman makes a distinction between the miss-credited, those with obvious stigmas and the possibly miss-creditable which are guarding a stigmatizing secret. Coping-mechanisms to escape discovery are described, as the person is doing everything he/she can to pass over to "the normal" society. The price is social tension and limited possibilities in life (Goffman1963).

CBR programmes In Ghana, Nepal and Guyana had positive impact on self-esteem, self-reliance, empowerment and social inclusion (Nilsson and Nilsson 2002). However impact was limited in physical well-being and confidence and trust in society to fulfil its human rights obligations. CBR-programmes continued to view persons with disabilities as beneficiaries, not as participants with a voice and a choice. Their influence was still limited, and their participation at all levels negligible.

Expectations towards assistance and support from community and district level had not been met. Many people with disabilities were not found or targeted. Medical care and rehabilitation services were still inaccessible for most people. Few CBR-workers had the skills to provide relevant quality advice on physiotherapy or rehabilitation-techniques, or to design assistive devices. A few days training without follow up was not enough (Nilsson and Nilsson 2002). In a CBR program in Afghanistan the parents were sceptical whether the CBR workers had the skills to deal with the various specific rehabilitation needs of their children (Turmusani 2004).

Mental Disability in Mexico

A report from Mental Disability Rights International (2000) described living conditions in several Mexican public psychiatric facilities. Lack of appropriate medical and dental care,

improper use of physical restraint and shortage of food, clothing, blankets and staff were found. Children were left tied to beds or wheelchairs most of the day. Care was not directed towards rehabilitation, nor did it assist to re-integrate people in their communities. It was estimated that 70% of the people with or without a mental disability were placed in long-term facilities, because they had no families and nowhere else to go. One-third to one-half was suffering from epilepsy and mental retardation. If provided with appropriate medication people with epilepsy could live in their communities. People with mental retardation would need a full range of community-service and support (MDRI 2000).

Piña Palmera

The rehabilitation centre Piña Palmera is situated at the Pacific coast in the state of Oaxaca in the south of Mexico. This NGO was funded in 1984, when some mothers of disabled children formed a small sub-community by the support of an American traditional healer. During 20 years of Mexican/Swedish leadership Piña Palmera has developed from an orphanage and some single mothers into a rehabilitation and education centre. In 1993 Piña Palmera started to work with CBR.

Setting

This study was conducted within Piña Palmera's target area for CBR work. The population consists of indigenous people, but there is also a mix of Spanish and indigenous people. They speak Zapoteco, Chatino and/or Spanish. Most people are small farmers. Some work in constructions, building houses or roads or run a small family business. Salaries are low and unemployment is high. Extended families are common, but that is changing because of migration. Many women and children work in the informal sector, selling food, clothes or craft. Tourism is a growing income source.

All political parties are represented. Catholicism is the official religion, but Christian free-churches are gaining ground. There is a Pre-Christian tradition with elements of shamanism and traditional healing, magic and miracles. It is mixed with Catholicism, forming a syncretism. Roads are insufficient. Public transports are few and unsafe outside the main roads. The telephone-net is deficient. Not all people in the villages have electricity, decent toilets or access to drinking water.

Significance of the study

A better understanding of how parents/guardians of disabled children perceive their life-situation is important for recruitment and support to local rehabilitation promoters. More disabled people could receive their rehabilitation and treatment at home. This would be cost-effective, practical and add to quality of life for many people.

Piña Palmera could improve and further develop its CBR-strategy, which will benefit the population in their target area. The results might be of interest to policy makers and local actors in the systems of health, education and social welfare. They could benefit from the results when planning their interventions. The study could add to the body of knowledge of CBR.

The writers pre-understanding

I am a Swedish nurse tutor and a midwife. My knowledge and experiences in this field are from working in a Primary Health Care - program in El Salvador in 2000 - 2001, training health-promoters. My main responsibilities were theoretical courses and practical support and supervision in a rural area 30 kilometres north east of San Salvador. In Mexico I worked at the rehabilitation centre Piña Palmera in the state of Oaxaca during 1997 - 1998, and 2003 to 2004, participating in the CBR-program and the activities at the centre. My work was directed towards teaching, health promotion and prevention. During these years I realized the difficulty to recruit health and rehabilitation promoters, and they frequently left the programs. I was wondering why, and that was the starting point of this study.

3. Aim of the study

The aim of this study is to describe parents/guardians perception of living with disabled children and their feelings about living with disabled children.

4. Methodology

4.1 Study design

In-depth interviews (Kvale 1997) and qualitative content analysis (Graneheim and Lundman 2004) were used. In the process of a qualitative research interview knowledge is created when the researcher and the informants interact and talk about a topic of common

interest. The researcher will always influence and be influenced by the participants in the study (Kvale 1997).

4.2 Characteristics of the participants

The informants were all part of Piña Palmera's rehabilitation program. They came from 13 different indigenous communities in the countryside and the fringe areas round the small towns. These settings were more or less assimilated into Mexican society regarding language, economy, culture, traditions and infrastructure. Sixteen informants were purposively selected to gain as rich and full information as possible. There were three fathers, two grandmothers, one adoptive mother and ten mothers. One interview was carried out with a couple. The informants spoke Spanish, though Chatino or Zapoteco were the native languages for a few. Many families were farmers. In households with female head of the family women and children worked in restaurants or sold food or clothes in the streets. All informants had very scarce economical resources except one. She was included in the study to get another perspective.

4.3 Data collection

Participants with different experiences, ages and gender as well as different disabilities and ages among their children were purposively chosen to get a broad variety of results. The informants were parents/guardians of 18 disabled children. Their ages varied from 3 to 15 years. Most of them had participated in the rehabilitation program for some years, but two had recently entered. The children's diagnoses were derived from medical records by doctors, physiotherapists, learning and speech-therapist, audio therapist and special pedagogues. They were also based on the information from the parents/guardians of the children and the researcher's observations. It was unusual that children had gone through a complete investigation and had a specific diagnose. There were hereditary congenital diseases, Down's syndrome and mal-formations, cerebral palsies, hemiplegics, learning and speech deficiencies because of brain damage, mobility- visual - and hearing - impairments, and Minor Brain Damage with hyperactivity and aggressive behaviour.

The writer was presented to the informants by a member of Piña Palmera's rehabilitation team. The aim of the interview was explained and confidentiality assured. Informed consent was obtained by oral information and an invitation-letter. The right not to answer a question or to end the interview whenever they wanted to was emphasized. Nobody minded the tape recorder. The author saw most informants one or several times, before the interviews were carried out, in order to build confidence and improve the quality of information.

Five interviews were done in the children's homes. The others were carried out at the rehabilitation centre or in the villages where Piña Palmera worked with CBR. We always tried to find a quiet and secluded spot, but where there are people there is a lot of noise. Houses were built according to tropical climate; they were opened or had no walls at all. Some tapes had disturbing background sounds, which made transcriptions more difficult.

Two pilot-interviews were done to test the questions and improve the interview-technique. They were later incorporated in the study. The last topic-area in the interview-guide was changed after the pilot interviews. The original intention was to ask the informants what they would need, in order to participate as rehabilitation promoters in their communities. Instead their opinion of the usefulness of a local rehabilitation promoter was asked for, to avoid that the informants felt uncomfortable and pressed, as it became apparent that they couldn't or didn't want to take on this task. They could have thought that the interviewer intended to convince them to become CBR-workers. They might have lost confidence in Piña Palmera's rehabilitation program and even left.

The interviews were semi structured. The opening question was: Could you please tell me, how you noticed that "Juan/Juana" was different from other children?

The parents/guardians seemed to trust the interviewer, and they appeared to be speaking from their hearts. They also told her about other traumatic events in the past, which were outside the interview guide. It wouldn't have been ethical to interrupt them. At two occasions the writer acted as a counsellor. The informants also brought up family violence and alcohol problems, though these topics were never asked for. All together there were six pages outside the topic guide. When very sensitive information had been given a last question was added. How did they feel about being an informant?

One interview was transcribed verbatim and translated before the next one was conducted. The intention was to learn from the former interview, modify questions and clarify statements and meanings (Dahlgren, Emmelin Winkvist 2003). In a qualitative research interview both interviewer and interviewees gain new insights and become aware of new perspectives. It is a potential learning situation (Kvale 1997).

The author carried out the interviews, the transcription and translation from Spanish to English herself. She asked the rehabilitation team about local expressions and meanings. There were 155 transcribed pages, page format A 4, letter size 12p, single space. The interviews varied from 30 to 45 minutes. All together there were eight and a half hours of recorded information. Five months were spent in the field.

Cross-checking of translation of the interviews has been done to improve the quality. One person listened to the tapes in Spanish and read the translated interviews in English. She is familiar with the context of Piña Palmera. Nothing that changed the content in the interviews was found. The psychologist at Piña Palmera, who worked under professional secrecy helped by listening to one interview, as the informant had a very difficult dialect. The psychologist knew the informant well, and nothing new appeared on the tape. The psychologist was also present during an interview with another informant. The person wanted the psychologist to be there. The quality probably improved, because the mother felt secure and confident.

4.4 Data analysis

Manifest and latent messages in the transcribed text were analyzed (Graneheim and Lundman 2004). The whole interview was considered a unit of analysis. Meaning unites were identified in the different content areas, specific areas in the text which shed light on the research-questions. Meaning unites were words, sentences or paragraphs which were related to each other through content and context. The meaning unites were shortened into condensed meaning unites. From these condensed meaning unites codes that could be understood in relation to the context were abstracted and labelled. The codes were sorted into categories. The categories referred to the descriptive level of the content, and were expressions of the manifest content (Graneheim and Lundman 2004). During data-collection and the first coding process it was important to let “data show themselves”. As the process moved on to analysis and interpretation, the writer’s knowledge and experience was important.

5. Ethical considerations

Permission was given by doctor Moises Montalvo Aspron in Servicios de Salud in Oaxaca, Jurisdicción Sanitaria no. 4. He was the chief medical district officer in the area. Permission was also given by the legal representative of Piña Palmera, the medical doctor Balbino Jesus Cano Pérez, who was responsible for the users' medical care. Informed consent by the interviewees was obtained by oral information and an invitation-letter. The right not to answer a question or to end the interview and withdraw when ever they wanted to was emphasised. Confidentiality was assured. Records and tapes were coded and anonymous, and kept at a safe place. The participants' identity and personal circumstances was protected at all times. Codes were used instead of names of persons and places. Some issues could be very emotional for the interviewees. The participants were respected. In no way were they pushed or obliged to answer a question that made them uneasy or uncomfortable. Every effort will be made to get back to them with the information on the results.

6. RESULT

The results from the analysis are presented in two sections. Section A; Parents/guardians perceptions of living with disabled children and section B: Parents/guardians feelings about living with disabled children.

Result section A; Parents/guardians perceptions of living with disabled children

This section consists of six categories (Table A).

Table A. Parents/guardians perceptions of living with disabled children

- A I Understanding of the child's disability
 - A II The child's rehabilitation is depending on the extended families' support
 - A III Society's impact on the child's' rehabilitation
 - A IV Attitudes towards disability are changing
 - A V Families needs in order to facilitate living with the disabled children
 - A VI The usefulness of a local rehabilitation promoter
-

A 1 Understanding of the child's disability.

Most parents/guardians were aware of the child's disability between one and three years of age. The child looked different or had a malformation. There was delayed psycho-motoric development and convulsions. They didn't hear/talk because of hearing impairment or they didn't see and move. There were also speech and learning deficiencies and behaviour disturbances. The informants went to many different actors to seek help. They visited the "Virgin from Guadalupe," (Mexico's National Saint), traditional healers, spiritists, nurses at the health centre, rehabilitation personnel and doctors; general practitioners and specialists. All children had been to a doctor and most of them were referred to specialist in Mexico City or Oaxaca. Some had to go to several hospitals due to broken equipment, lack of hospital beds, specialist competence or knowledge. There were no adequate transports. It was expensive to pay doctors, medicines, operations and travel-costs. If they didn't pay, the child would not be discharged from the hospital. Staying away from home with the disabled child implied that they couldn't work.

"When he was newborn, his head was full of liquid and at the back a part was opened, and he was bleeding. I asked for an ambulance. There was none. In Oaxaca the doctor didn't attend the boy. I had to go to another hospital. The boy was very bad. I was fighting the doctors. He got a shunt. "(3)

After the initial intentions to find a cure and/or provide rehabilitation for their children, most parents/guardians couldn't afford it any more. They lacked insurances and had very low incomes. They had to leave the children at home the way they were. They felt they couldn't do anything to improve their lives.

"We paid extra to a private doctor. It was expensive. We are not beneficiaries. We had to leave the boy at home the way he was. We couldn't do anything". (2)

Information about the disability was given by all the actors mentioned above. On the local level more than half the information was incorrect or simply missing. To receive correct information they needed to see a specialist in Mexico City or Oaxaca. Though the parents/guardians had seen many doctors, some didn't have an adequate understanding of the child's disability. They were still wondering why it happened.

“She had a haemorrhage in her little head. She would not be normal, she would be retarded. She would not walk or learn when she went to school. I thought she would be late in her development, but then she would be ok.” (10)

A II The child’s’ rehabilitation is depending on the extended family’s support

Most informants had support from their extended families. They often lived together. Grandparents, uncles, aunts and the informants’ own children were important. The children were accepted and loved. The family knew them and thought of them as normal. It was important to have another child soon, so he/she could play with the disabled child, and take care of him/her in the future when the parents wouldn’t be there. But family patterns changed. Parents died, children grow up and left. Many had relatives in the US.

“Our daughter helps us. We have three grown up children in US. They send a little money. We live together with my husband’s brother’s family. We go and talk to them. They support us. They have a cow; they give us milk or cheese for J. and L.” (14)

The family was doing the rehabilitation/ training at home. They saw improvements and development, and were proud of their children when they performed well. They brought them where Piña Palmera worked with CBR or to the rehabilitation centre. A family risked their lives by walking through a deep and strong river during the rainy season, to bring the boy to sign language classes. A girl had an ocular-plastic surgery and Dolphin-therapy and went regularly to a private institution for visibly impaired children in Mexico City. The families also gave massage, home-remedies, medicine and took care of pressure wounds. One informant described how the parents/guardians got organized and obtained a place for rehabilitation in town. She was proud about it. It was worth the effort.

“We got organized and got a place for rehabilitation from the president. We cleaned and painted. We asked for furniture; everything had been stolen. They put in water, there is even a toilet. We made an effort”. (7)

One woman had an alcoholic husband. The extended family was withdrawing their support because of his behaviour. There wasn’t enough food or money for clothes or schools.

Violence was common at home and in the society. To some it was natural, they didn't even reflect upon it. A grandmother just started to see the connection between the violence in the family and the boy's hyperactivity and aggressive behaviour. The psychiatrist had told her to give the grandchild love and understanding, but she couldn't handle his behaviour.

"He is aggressive and doesn't obey. I threat him to leave him with his godfather. I say; "don't do this, you hurt your sister!" He does it ten times. I get tiered and hit him" (12)

Beating up children "for their own good" was an accepted way of educating children. Other informants believed in love and understanding.

"The children are following the pattern. If you plant a crop well, it will give you fruits. If you don't give it water, it will give you nothing". (3)

A father was shot in the spine. People told the mother she would not be able to take care of her children. She had five boys and one disabled girl. They demanded that she should give them her boys.

A III Society's impact on the child's rehabilitation

There were magical beliefs in the families as well as in the society concerning the cause of disability. "The eye" and "evil forces" were known to most people. Somebody cast a spell on the person, but it would fall upon the children. Certain actions on the parents' behalf could cause a disability. They had problems with the people where they lived. They were punished because they were "bad"; the father ran with other women ore the mother had been angry. The mother's anger could cause convulsions. Disability was mostly blamed on the women. It could even be God's punishment. It was the parents fault. They were guilty and society was judging them. These beliefs were taken very seriously.

"People do sorcery. They wanted to do me harm. The curse wouldn't fall upon me, but on my children". (14)

Some felt sorry for the disabled children. Others kept silent and didn't care as long as the disability was outside their own family. Each one arranged his business. Some gossiped

and made fun of them. Disability was also considered an illness, and people thought they could be infected.

“People change place at the bus station. Mothers pull away their children. “Is he ill? Don’t get close; you can be infected.” People stare. It makes me furious. Who are they to judge? I have to face it.” (6)

A common attitude among others was that rehabilitation was a waste of time, according to the informants. People went once or twice and saw no difference. They wanted immediate results, miracles. Or maybe the problem would resolve it self, if they just waited.

“Others, poor ones they don’t bring them out. They don’t want to waste money on transports. They are locked up in their houses. Let’s see if he dies this poor one!” (11)

A IV Attitudes towards disability are changing

Old beliefs were slowly replaced by a new awareness in the communities where Piña Palmera worked with CBR. People in the streets were positive. Parents /guardians were encouraged to keep on fighting, seek information and bring their children to doctors, rehabilitation or schools. Some received acts of charity for their children. The psychologist from Piña Palmera was conducting parents’ self-help groups. It was appreciated and confidence-building. Teachers were generally supportive. A mother talked to the headmaster. The class mates took care of her hearing impaired boy. Parents started to send their disabled children to school. Pick up trucks didn’t charge them. Disabled children were taken to health centres and rehabilitation.

“Thanks God these people from Piña come over here. Disabled children start to get to the health post.” (2)

Authorities were planning to build a rehabilitation centre in X-town. Families with disabled children were supported. The local presidents helped with transports to come to Piña Palmera and paid the petrol for the centre’s out reach service. The parents/guardians in a small town received a place for rehabilitation from the authorities. A governmental institution “Integrated Family Development” (DIF) gave dispenses and some money, but a

birth certificate was needed. They used to have a milk program. They had access to doctors and supported a few informants with costs for journeys to specialists and shelter in Oaxaca.

A V Families needs in order to facilitate living with the disabled children

Money, food, support from authorities, information on disability issues, access to health, rehabilitation and schools were asked for. Disabled children had special needs like assistive devices, medication, medical appointments and transports. Care required time and single mothers had no one to leave the children with when needed. Sharing with others was appreciated, but a parents' organization was missing. One informant was illiterate.

Money was most important to all informants. Many families were small farmers and gained just enough to survive. Some went illegally to US for a time. Some never came back. The women worked in restaurants, washed clothes or sold food in the streets. Their children helped them. Two informants took private loans with high interests.

My child was in the hospital. I didn't have any money. There were days we didn't eat, we lived like...The medication was very expensive, and the operations. (3)

Many mentioned lack of food for themselves or others. The families were big. Programs with supplement food were important to them. They knew milk was good for the children, but they couldn't afford it on a regular basis.

"We are eleven people at home. I cook five kg of maize a day. Milk helps the children, but it is expensive. When I see a cow, I buy four litres for 20 pesos." (14)

Support from the authorities was asked for. They wanted DIF to give dispenses and grants for their children. The local president could make agreements how to arrange the parents and children's needs. In one community they wanted a bigger place to work with rehabilitation. There were lots of children who needed support in their development.

Authorities ask for papers, copies of the birth-certificate, electric bills and who knows what more they ask for. They NEVER HELP US!!! My son cannot do anything. This poor one doesn't go to school, so there is no support. (11)

Access to information and health service was problematic, as mentioned earlier. People had to travel considerable distances, and medical care was too expensive. A clinic in the mountain didn't charge at all. Some children received anticonvulsive medication for free; others had to pay for the same treatment.

The doctor prescribed a medicine; it was very expensive. After a month the money was finished. We don't bring them to the doctor anymore. (14)

Rehabilitation was perceived as an important need. It was appreciated that Piña Palmera came twice a month to the communities. Their children were developing. As Piña didn't charge, the people could keep bringing them. And they didn't have to travel that far.

"We bring him where Piña works, they don't charge. That's why we can do it. It was expensive to go to Oaxaca and Puerto Escondido. He is so much better, more sure of himself." (9)

The disabled children had many special needs. Daily care took a long time. Some said it was like caring for a new born baby. The informants didn't have anyone to leave the children with when they worked, participated in meetings and programs or needed a rest. They brought them wherever they went. Children were also heavy to carry. Tickets for journeys were a problem for all families. Children from remote areas were not taken anywhere.

A disabled child needs many things; diapers, special attention, therapy, wheelchair, medical consultations, medicine and tickets for journeys. You pay everything. (4)

School was another expense. The parents/guardians paid inscriptions, uniforms, photos, materials, shoes and co-operations. Voluntary work was also required. Special schools were badly equipped, had few teachers and no therapists. A girl with learning and speech deficiency didn't receive help with her homework, because her mother was illiterate.

I have four children at school. I have to pay uniforms, shoes, cooperation, admission fees. I can't read, write or work. I can't help her with homework. (8)

Women were abandoned by their partners and became head of their households. They worked in the informal sector and took care of their children, with and without disabilities at the same time. There was little or no support from the fathers.

“It has been terrible those ten years; economically and emotionally. Without tranquilizers he is unbearable. He hurts himself; he bangs his head against the wall and bites himself. I am awake all night. The boy’s father didn’t support me. I denounced him. He doesn’t pay, I can’t force him.” (6)

Sharing with others was appreciated, but the informants hadn’t organized them selves. They didn’t come together except when Piña came to work with CBR. In the parents self-help groups they talked about their difficulties and went home feeling more tranquil and confident. If the parents were organized, it would have been different. If they had all gone together to talk to the authorities, they could have obtained their rights.

Nobody told the governor that we needed help. If we were organized we could ask the president for grants for the children. They need it. If we all did go, ten to fifteen parents, it would be different. (13)

The disabled children needed to become independent. One informant thought the parents didn’t want to work together. They lacked enthusiasm. There was also a reluctance to admit /accept the problem. They preferred to deny the disability.

We need to make parents aware, to accept the problem and make disabled children independent. We, the parents don’t last for ever. We have to form groups and fight for our rights. The awareness isn’t there yet. (6)

A VI The usefulness of a local rehabilitation promoter

The informants said that a local rehabilitation promoter would be most important. The children needed rehabilitation to develop. In X-town the authorities were going to build a

rehabilitation centre, but it was uncertain whether it would include staff or just the building.

The parents felt alone and needed support, information and teaching to be able to do the therapy at home. If there was a rehabilitation worker in the community, therapy would be more consistent. The situation would change. Disabled children could be detected earlier. Many learned to eat, walk or talk until they were five or six years old. The parents said it was normal that way; until they were five or six they had to learn these skills. Health centres were not covering the special need for rehabilitation. Doctors didn't have the time or the knowledge. Doing this was a specialization.

“The doctors will only give medicine, but if the child needs something else, sign language for example, they will not be able to do it. They don't have time. They have another work and they don't know.” (5)

The rehabilitation promoter would need a salary to cover his/hers expenses. No one would work gratis. It was impossible. It would also imply a serious commitment to the task. The authorities could support the person, or the parents could give a small cooperation. One informant wanted voluntaries to come to her house. But she thought people were not interested, they only wanted the money. The rehabilitation promoter would need a set place to work and equipment. Follow up cases required time. One had to do the work at home first; they couldn't go and attend problems of others. It was difficult. The person would also need education, a course. The parents needed to organize them selves to support the rehabilitation promoter to detect and work with the disabled children.

“It cannot be a volunteer for a permanent time. They need to gain food and pay transports. Gratis is impossible. I think of support from authorities.” (13)

Result section B; Parents/guardians feelings about living with disabled children

This section consists of seven categories (Table B).

Table B. Parents/guardians feelings about living with disabled children

B I Reactions when realizing the problem; wanting the child to be normal

- B II Withdrawing socially because of not being good enough
 - B III Giving up hope for support from the society
 - B IV Being determined to stand by their disabled child
 - B V Encouraging others who live with a disabled child
 - B VI Feeling good about the disabled child
 - B VII Wanting to abandon the disabled child
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B I Reactions when realizing the problem; wanting the child to be normal

Receiving information about the disability was hard. Interviewees expressed feelings of despair when realizing the problem. Their child was just about to die. They negotiated and gave promises to God. When the children were hospitalized the parents were not allowed to be with them. One person even wished that her daughter would die. The girl had been crying and vomiting for a month before she was admitted to the hospital. The mother never slept. The parents felt bad, they cried for their children and didn't know what to do. They questioned: why did it happen and why me? Many felt guilty. They accused themselves and regretted things. They felt powerless, because they couldn't help their children.

“There is nothing to do. There is no cure for the bad thing in his head. He wasn't normal. How he has suffered from this, the boy! One is suffering with them.” (2)

One mother regretted spending so much money on her son; after five years it turned out that he had something else. Some refused the information given. They kept seeking” a second opinion”. Some were helped by their religious beliefs and hoped for miracles.

“The doctors all said the same. The girl would never see. She was blind from birth. She had a psycho-motoric retardation. I searched in many hospitals and centres in Mexico City. I went to the “Virgin of Guadalupe” and offered masses. She can see a little now. She is learning to read.” (15)

There was a tendency to overestimate the child's capacity. A mentally retarded child was very intelligent. Children who spoke a few words spoke very well. A girl with Mb Down

understood everything. A child who didn't hear at all heard strong sounds. Unrealistic hope still remained; a child who had been paralyzed for twelve years might start to walk. The disability was not fully comprehended or accepted. They wanted their children to be normal.

One person underestimated the child. Not all parents/guardians were familiar with normal development. Children were "borne well", though they were born premature. A couple tried to teach their three years old boy to read, so he should learn to talk better.

"We asked the doctor for a cure so she could be well, normal. There was none. We went on fighting; we saw lots of doctors and also the "curanderos" (the traditional healers). They all said the same. To me she is a normal girl. She is not ill. She has her disability, that's all." (1)

B II Withdrawing socially because of not being good enough

The informants perceived that other parents didn't value or pay attention to their disabled children. They didn't bring them outside because of shame. They were not taken to school or rehabilitation. Single mothers needed to work. They had no time. People thought the parents with disabled children didn't want to participate in the society. They didn't understand that caring for a disabled child required time. The adoptive mother met surprise from her friends. How was it possible that she took care of this child? The ministry told her to give the girl to DIF for adoption.

Disabled children were rejected by normal children. They were not good enough to play with. At school they were ridiculed and beaten. Disabled children felt uneasy, shy, ashamed and nervous. They stayed home and watched the others playing. Parents felt bad, guilty, insecure and ashamed because of society's rejection. They withdrew socially. People laughed at their children. It took strengths to meet the community! Some had developed this strength. They didn't care. Others became furious. One mother told the community, not to reject her child. They could get a disabled child themselves, because they were rejecting hers.

All informants brought their children outside, though they hadn't always done so. Especially the girls had been hidden for years. Parents/guardians wanted to protect their families. Some only brought the children where they met sympathy like the Christian Free Church or Piña Palmera's rehab centre.

“ I always felt guilty. I don’t feel bad about the girl. I bring her to the temple. My neighbours don’t see her. She ought to be with her mother.” (10)

Grandmothers were more outspoken than the parents about the children’s disabilities. One accused her daughter-in-law for causing her child’s disability by going to the doctor to give birth. At home they were born easily; they came out just like that! Another said the parents didn’t love their children. The mother didn’t want them. Grandma of an adoptive girl never agreed to the adoption. The girl was taking her daughters time. She would never go anywhere. She had no one to leave her with.

B III Giving up hope for support from the society

Many informants were disappointed with the authorities. They didn’t help single women in debts. They didn’t give grants to the disabled children. They asked for papers and documents, but they never helped them. “Oportunidades” was a governmental program for support to the poorest families in the country. They gave a small amount of money every month, but certain obligations had to be fulfilled. The women had to clean the road-sides and come to meetings at the health clinic. The small and disabled children were with them. One informant was upset; it was dangerous for the children on the road. The women also had to pay a co-operation to the program. The informant felt used and humiliated.

“I went to the authorities to ask for a grant for her. They cheat me; they say yes, but no... The president knows about the girl. She doesn’t support us. She sends someone to say she is not in, but she has gone up on the second floor.” (8)

The authorities should be more involved in special education schools. The conditions were deficient. There were not enough teachers. They didn’t have the education needed. The classrooms were in a terrible state, as well as the toilets. Equipment was missing. The directors’ board didn’t do anything about it. One person thought of sending an announcement to the governor or to DIF in Oaxaca, so the school could function. Some children were mal nourished. Parents didn’t go to meetings at school. The psychologist gave workshops, but the parents were not interested.

There were frequent complains about the accessibility and quality of health care. It was too expensive. The attitudes of the doctors and other staff were discouraging. Many didn't trust the information or treatment given. They felt the doctors weren't honest. They had seen their children become disabled in the hospitals.

“My girl didn't react after the operation. The doctor said she was fine. She would recover in two months. The paediatrician in Mexico City said her breathing stopped during the operation. Her brain was damaged. She will not be well. But she was born normal. She had started to walk.” (13)

Attention during birth was deficient. Traditional midwives were the first option, especially in remote areas. Medical attention was also deficient in the health centres and local hospitals. One woman decided not to have another child because of a complicated, traumatic birth and feelings of guilt, sorrow and suffering.

“They kept me at the health centre all night. I was referred to the hospital too late. The girl has a cerebral palsy. “Why was my girl born like that?” I felt unhappy and said I wouldn't have more children.” (10)

B IV Being determined to stand by their disabled child

Parents/guardians were determined to stand by their disabled children. They loved them and wanted to help them go forward in life. They wouldn't abandon them. In the future they expected their healthy children to support them.

“I will fight for my children. I will eat tortillas and salt with them, but I will stay with them. Tomorrow they will grow up and help me.” (1)

The informants' religious beliefs helped them to overcome the daily struggle. They asked for strength to do God's will, to accept the suffering. God would also arrange the justice with the husband who abandoned them. Some fathers went to the US to gain money. It was heartbreaking to leave the family, but they saw no other option.

“I will help my girl if God gives me health. I ask for strengths to do his will, accept and not be angry with the children, no one. One ought to accept. There is more peace inside, as if my daughter wasn’t like that. God wanted it; I can’t reject or deny what happened. Doctors are also under God’s will.” (13)

B V Encouraging others who live with a disabled child

All informants knew of other families with disabled children. They encouraged them to bring out their children in the society and take them to therapy. It was bad that they were hidden at home. The parents/guardians said they didn’t understand why others felt ashamed and accused them for not taking care of their children. They were irresponsible and ignorant. They didn’t want to know of the problem. Though several informants had gone through these experiences themselves, they were quite critical towards others. One grandma offered to bring others’ children as well. The parents/guardians were aware that they were positive models for those who didn’t have the courage to face society’s prejudices.

“You should go; I have gone for four years. If you don’t take care, your children will not go forward. I will bring yours!” (7)

B VI Feeling good about the disabled child

When difficulties were overcome or accepted many informants said they were happy. They were helped by the support from the family and the trust in God. There was an existential meaning to their lives. God had sent this child to them for some reason. So they loved the child and took care of him/her. They also got to know children with other kinds of disabilities, which they considered more severe. Then their problems diminished. With the rehabilitation the parents/guardians also saw development that gave them hope for the future. They felt good about their children.

“Now I feel happy and calm. I feel good about my boy. I have faith in God and in them. /Piña Palmera/ My son will go forward at school. It would be sadder, if he couldn’t move or think”. (5)

“I am happy with my daughter, of course I love her. God knows why He sent her to me. I take care of her. She is my greatest happiness.” (15)

B VII Wanting to abandon the disabled child

Some wanted to leave the disabled children and all the obligations. They were just there to work for them. Fathers often abandoned their families. A disabled girl was abandoned at a wealthy family’s home.

“They left the little girl to me when she was three days old. My servant said: “Look what they have left here! A señor told me to look after her, he was going to buy milk, she was hungry.” She had no clothes; she was wrapped up in a blanket. He never came back. I saw a lawyer, to know what to do. A report and an order for detention for abandoning an infant were written’. (15)

7. Discussion of results

The parents/guardians in the study were poor or extremely poor. Results showed that they were aware of the child’s disability before three years of age. They wanted a normal child and most informants spent time and resources they couldn’t afford to find a cure. Poverty, lack of insurances and traditional beliefs impeded access to information, health care, rehabilitation and schools. The child’s rehabilitation and integration depended on the extended family, and single mothers had little or no support. They needed help from the authorities. Stigmatization and discrimination made the parents/guardians withdraw socially and the disabled children were left / hidden at home. Where there was a CBR-program there was more knowledge of disability issues and collaboration by authorities, health personnel and teachers. A local rehabilitation promoter would improve quality of home-training and rehabilitation, but the informants couldn’t take on this role, as they needed to work to maintain their families. The rehabilitation promoter would need a salary, equipment, a place to work and support from a parents’ organization in order to carry out the CBR-work. When parents/ guardians received information, treatment and rehabilitation for their children they saw improvements and development. Trust in God was a great motivator, and they felt good about their children

The parents/guardians in the study were poor or extremely poor

All informants mentioned need for money and food. However, they never used the word “poor” about themselves. They said: “we lacked the financial resources”, or “we didn’t have the money”. It would have been interesting to know, whether they considered themselves poor or not, as they lived in a context where poverty was the norm for many. Their living conditions were similar to what Lewis (1961) called “culture of poverty”, described in his anthropological research about Mexican families forty years ago.

Five percentage of the Mexican population and eight percentages of children under five are mal-nourished. UNICEF has mentioned that 30 000 children per year are dying from mal-nourished-related conditions. Half the population in Mexico lives under the poverty line, and 20% live in extreme poverty (UD 2004). One person who belonged to the upper economical class was included in the study. The difference was reflected in early awareness of the child’s disability, the stimulation and amount and quality of therapy that the child received. This child made impressive progress. The mother had faced the same prejudices as the others and hadn’t received any support or information from the authorities. She had arranged everything herself.

Wanting a normal child

Parents/guardians experienced a full range of crisis reactions when realizing the problem. In the first place the child’s survival was threatened. Then there were psychological defence-mechanisms (Cullberg 2003) because of the disability and its possible consequences. Some parents kept seeking a second opinion. They overestimated their children’s capacity and maintained hope for miracles. Maybe the child would start to walk after being paralyzed for years. This was in accordance with their religions, traditions and personal needs.

Overestimation gave a sense of having a normal child. Identity and self-confidence which had been affected by stigmatization were restored. This could be seen as coping-strategies (Goffman 1963). But overestimation could also be an expression of acceptance. The child was normal to the family. Underestimation and overprotection also existed. There was little knowledge about children’s normal development and the importance of stimulation.

The parents/guardians cultural beliefs were reflected in their help-seeking behaviour.

Children from remote areas were brought later to rehabilitation and treatment. Traditional healers were sometimes consulted first. Early intervention was delayed. This was also found by Nilsson and Nilsson (2002).

Poverty, lack of insurances and traditional beliefs impeded access to information, rehabilitation and the health system

Turmasani (2004) and Nilsson and Nilsson (2002) described that in poor communities in Afghanistan, Ghana, Nepal and Guyana access to health and rehabilitation was difficult if not impossible due to costs and distances. The Mexican health-system is too expensive and quality of care is low, which was verified by Tamez, Molina (2003). Families had no health insurances. The children's special needs were expensive. People travelled far; they became poorer, and were further disempowered. Caregivers' attitudes were important. Information from doctors wasn't always understood. Venter (1997) writes that parents/guardians who were referred to a specialist hospital in South Africa had some understanding of the child's disability. They had earlier received poor counselling and there were language barriers and initial states of shock. Some indicated that they hadn't received any information, which was interpreted as part of the denial phase. They hoped for a more acceptable diagnose. After the specialist consultation correct understanding decreased. Some were really confused, maybe because of the mismatch of divergent models held by parents/guardians and professionals about what was wrong with the child. However there was a significant increase in understanding of the aetiology, and 82% of parents/guardians were satisfied with the consultation. This result could be a reflection of the consultation according to the researcher. Aetiology was less stressful and more readily discussed by doctors. If compared to the present results of this study in Mexico, maybe the parents' satisfaction was linked to releasing guilt and shame.

Access to the health system was a problem during birth. Traditional birth attendants were the first option for many women. At night transports were few or absent. In the governmental hospital relatives were not allowed to be with the patients. The decision not to have another child was unusual in a society where it is important to have children. The mother had suffered tremendously from birth and from having a disabled girl. She had maintained her decision for 13 years.

In rural Oaxaca the traditional birth attendants (TBA: s) assist almost 50% of births according to Galante Di Pace, Gil Archundia (2005). They are preferred by the mothers because they are women, they charge less, they attend the women at home, speak the same language and share the same values and cultures. They are trusted by the mothers and families, though they also recognise their limited possibilities to intervene when serious obstetrical complications occur.

The child's rehabilitation and integration depended on the extended family

The extended family formed the social-economical network. It was difficult to find someone to leave the children with, if the extended family wasn't willing to take care of them. This created a heavy pressure on the parents/guardians. They became isolated and couldn't participate in community activities. Single mothers were especially vulnerable.

The informants did the rehabilitation/training at home. It was important to come to Piña Palmera's rehab centre or outreach service in the communities. In a CBR-program in Ghana (Nilsson and Nilsson 2002) parents' interaction with the disabled children increased. They trained them in daily living skills and allowed them to try new things. Children became more self-reliant and even contributed to household activities.

The informants said that rehabilitation was considered a waste of time and money by others. Many families had to choose between working to gain food or bring the disabled child to school and rehabilitation. As resources were scarce they actually had little choice. According to WCPT (2003) disabled children are not seen as a priority for investment and development in many poor communities worldwide.

Special education schools, where they existed were deficient. As education wasn't free, many disabled children didn't go. The opinion on inclusive schools was divided. A few children benefited from it, but many experienced humiliation and lowered self-esteem. This result was in accordance with Nilsson and Nilsson (2002). As a consequence of the serious exclusion encountered at school, disabled children remain at the margin of progress and development (INEGI 2004).

Violence and alcohol were probably underestimated determinants in causing or deteriorating a disability. It was also common that fathers abandoned their families. There was little support from the authorities according to most informants. Nobody mentioned existing laws. The disabled children in Mexico (INEGI 2004) are forgotten, not recognised and the families do not know their rights. They remain in their homes or institutions of custody where professional personnel and equipment is lacking.

There were feelings of anger and disappointment towards society. Like most people who live within a "poverty-culture" (Lewis 1961) the informants were suspicious towards the government and the authorities. Governmental help-programs to keep the population alive, but didn't deal with the roots of poverty reinforced feelings of helplessness and suspicion.

Withdrawing socially because of not being good enough

Stigmatization and discrimination were common at the community level. In Afghanistan and Zimbabwe disability was mostly blamed on the mother (Turmusani 2004, Banda 2002). In Mexico men were not blamed for causing the disability to the same extent as women because of *machismo*. The belief in male superiority, *machismo* and the corresponding martyr complex among women still played an important role in society (Lewis 1961). Explanations how disabilities were acquired coincided with other studies in the world by Groce (2001), Banda (2002), Coleridge (1998), Turmusani (2004). It was a matter of Divine order, fate and beyond anyone's control. It was strongly attached to guilt and shame. The parents were punished because they were "bad" people. There were also concepts of sorcery, and the misconception that disability was an infectious disease. Society was judging them.

Parents/guardians and their disabled children withdrew because of existing attitudes and actions. As they had internalized these concepts to a greater or lesser extent, they felt guilty and ashamed. They had experienced stigmatization for being indigenous people, poor, women and parents of a disabled child, all the classical marks of stigma (Goffman 1963). Stigma seemed to be stronger if the woman had given birth to the child. One informant emphasized several times that she was the adoptive mother, not the biological. Another repeated over and over again: "my girl was born normal. She had started to walk!" They were not guilty. Coleridge (1998) argues that congenital disabilities were often regarded as shame and largely absent from public view in Afghanistan. Parents claimed that their children became mentally retarded from a bomb attack to conceal the congenital nature of the disability. Hiding the disabled children could be seen as coping mechanisms to overcome stigma (Goffman 1963). As the disabled children were unknown to the community people reacted with fear, curiosity or rejection. Society needed to become familiar with persons with disabilities. The children were not targeted in mainstream programs for health and development. They were deprived their human rights which are stated in Mexican laws and the Convention of the Rights of the Child article 23(3) about physically or mentally disabled children's rights.

The impact of a CBR-program

However there was a slow change in attitudes and beliefs towards disability. Processes of awareness rising and empowerment as part of the CBR-program had an impact. There was collaboration with the authorities, teachers and health workers. In X-town the authorities were planning to build a rehab centre. Children were taken to schools, rehab and health centres.

They became visible. Charity is counter-productive to development (Coleridge 1998) because it maintains status quo. Charity was strongly rooted in Mexican society.

There was a need for sharing experiences and emotions with others. Parents' self-help groups were appreciated. They need to be further developed into stable parents organisations, which can identify needs and take collective actions accordingly. The informants were aware that they were positive models for those who didn't have the courage to meet society's prejudices. They encouraged others to bring their children to health centres or rehabilitation, and felt good when they could be of help.

The usefulness of a local rehabilitation promoter

A local rehabilitation promoter would make a difference in the communities. Quality of rehabilitation would improve. Children with disabilities could be detected earlier. In spite of this no one was able to or willing to take on this challenge. They all needed to work to maintain their families. The rehabilitation promoter would need a salary, a place to work, equipment and education. The authorities could pay the person; the parents wouldn't be able to do it. The parents/guardians support would be necessary in order to find the disabled children and to participate in the rehabilitation. The informants probably assumed that the rehabilitation promoter would be someone from outside the community who had the required knowledge and skills, but wasn't familiar with local conditions. Nilsson and Nilsson (2002) found that local rehabilitation promoters couldn't work under existing financial conditions. CBR-programmes should influence/ pressure governments to provide community workers with back up, continuous training and incentives. ILO, UNESCO & WHO (2004) state that community-workers need knowledge and skills as well as continuous supervision on how to assist the disabled people. This has to be provided by the professional CBR programme management.

There was no parents' organization except Piña Palmera's self-help groups. The reason for this has to be investigated further. Maybe it was due to stigma, or the "poverty-culture", where there is little or no organization outside the family. According to Nilsson and Nilsson (2002) disabled people's organization can play two roles: advise and put pressure on government authorities and empower their members. They need help to take on this role. Parents' organizations need assistance for capacity building and voicing.

The health centres didn't cover the special need for rehabilitation. Primary Health Care lacked competence to make correct diagnosis and treatment which was also described by Nilsson and

Nilsson (2002). Medical care required resources and knowledge that were not available at the community level. WCPT (2003) has pointed out that a stronger orientation towards rehabilitation in primary health care service is needed.

Adequate information, rehabilitation and trust in God gave hope for the future

It was moving to see and hear the parents/guardians express their deep emotional commitment to their children. They were determined to stand by them as long as they could. Temporary illegal migration was a solution to gain money, pay debts and create a better future for the family. They also took private loans with high interests.

Catholicism was important as a gathering point in a world where there was no social security and the future for the children seemed insecure. Trust in God gave strength to overcome daily struggle. God had sent the child to them for a reason. There was an existential meaning to their lives. It was their lot in life to suffer. There was also certain nobility in suffering. This could be taken to ways. The Catholic Church repressed the women, or their religious belief was a great motivator that gave strengths in daily life.

Parents/guardians needed help to come to terms with their situation and accept the disabled children just like they were. Parents who joined a CBR-program in Guyana described how their attitudes changed from being sad and ashamed to become proud of their children (Nilsson and Nilsson 2002). If adequate information and rehabilitation was provided, the children made progress. Self-confidence and self-esteem increased in both parents/guardians and children.

When evaluating the interview situation the informants expressed that they felt good about sharing their thoughts, feelings and experiences. They said they released the emotional pressure and felt alleviated. They also felt it was important and wanted to contribute to improve the situation for families with disabled children. One mother felt sad, upset because of worries for the future.

8. Conclusions

Disabled people's rights in Mexico are protected by national and international legislation. In the state of Oaxaca only 24, 3% of the total population is covered by social security. The health system is too expensive, and quality of care is low. Primary health care doesn't cover disabled children's needs, and information on disability issues is lacking. Poverty,

ignorance and stigmatization interfere with rehabilitation and integration in society. A local rehabilitation promoter would improve rehabilitation and early detection, but he/she needs a salary to carry out the CBR work. All informants knew of other disabled children who were kept/ hidden at home. These children are still waiting to be found.

9. Methodological discussion

Limitations as language barriers were expected. Misinterpretations of words and local expressions were avoided by access to Piña Palmera's staff. Coming back to Piña Palmera in a different role and with a different objective was difficult. The rehabilitation team that the researcher had worked with for years expected her to participate in their daily work. She had a conflict with double roles. They were informed about the study, and had read the interview guide.

In qualitative content analysis (Graneheim, Lundman 2004) the concepts of credibility, dependability and transferability have been used to describe aspects of trustworthiness. The characteristics of the informants, the children's disabilities and the socio-cultural contexts were described in the methodology section. As the study was limited to persons who were part of Piña Palmera's rehabilitation program, it doesn't show how other families outside the program perceived their situation, living with disabled children. Regarding transferability "*Machismo*", the cult of masculinity is a Latin American concept which has a heavy impact on all aspects of life in the society. Traits of machismo are found in most cultures; gender equality is a challenge. Handling stigma (Goffman 1963) is a general trait in society, a process that exists everywhere where there are identity norms. The same traits are found whether it is about big deviations or a small detail, that the person is ashamed of feeling shame about. Stigma is about relationships and norms in the society. Disability is closely linked to poverty. "The culture of poverty" (Lewis 1961) is a sub-culture, a way of living. It is a coping strategy to survive hardship and pain which would otherwise be unbearable. The findings in his anthropological research "The children of Sanchez" highlight the economical, social and psychological circumstances that have impact on people's lives. They show what poverty does to people. Lewis has found "poverty-cultures" in many different places like Puerto Rico, London, Mexico City and the

USA. It is a cross-cultural phenomenon and was also found in this study. Having said this it is still the reader who decides about the study's trustworthiness.

10. Recommendations

Parents/guardians expressed a need for more information. Piña Palmera sends a 15 minute radio program twice a week which could be extended. Parents' self-help groups need help for capacity building to empower their members. Piña Palmera could give courses on basic rehabilitation techniques and prevention. Local authorities need to be more involved in disability issues. The community could choose a person to become a rehabilitation promoter and send him/her to courses. The person would need a salary to be able to fulfil his/her task. School fees could be taken away for children with disabilities. Transports could also be free in order to facilitate access to schools, rehabilitation and integration in society.

Primary health care need to improve the knowledge on disability issues and be more directed towards rehabilitation. More information on prevention is also needed, and judgemental attitudes must be avoided at all times. Medical consultations and long time medication should be free. Disabled children need to be detected and targeted in main-stream programs for health and development. Special interventions and support to single mothers are urgent. Prenatal care and assistance by medically trained personnel during birth is important. Lack of infrastructure is an obstacle in remote villages. As the informants first priorities were money and food for their families it became obvious that disability is a matter of social, economical and political justice.

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Attachment 1:

12. Information letter

Would you like to participate in a research interview about families with disabled children's life conditions and needs?

My name is Klara Stintzing. I am a Swedish nurse-tutor and a midwife. I am studying at the university in Uppsala in Sweden in a Master programme in international Maternal and Child Health.

If you agree to participate, I would like to interview you for about 45 minutes. I will use a tape recorder, so I do not miss anything important that you tell me. Your participation is voluntarily and your identity will not be revealed in the report. Names and locations will not be mentioned. Tapes and notes will only be handled by the research-team and kept in a locked place. When the study is finished, they will be destroyed.

If you do not want to answer a question, you do not have to, and you are free to withdraw from the study at any time.

I can not give you any money or incentives for your time, but I hope the results will be of help to improve life conditions for families with disabled children.

This research is carried out as part of a master training programme at ICMH, International Maternal and Child Health, Department of Women's and Children's Health at Uppsala University, Sweden. Dr Pia Olsson is supervising the study and her address is given below.

If you have any questions, you can are welcome to contact me at Piña Palmera until the beginning of December.

Phone-number: 958 31 45

Thank you for giving me your attention!

Klara Stintzing
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Attachment 2:

13. Topic guide:

1. The interviewees understanding of the child's disability.
2. The family's attitudes and actions towards the child.
3. Community's attitudes and actions towards the child.
4. Special needs as being parents/guardians of a disabled child.
5. The usefulness of a local rehabilitation promoter and what this person would need to be able to do the CBR work.

Attachment 3:

14. Interview guide and follow up-questions:

1. The informant's understanding of the child's disability

1. 1 How did you realize that your child was different from other children?
1. 2 When did you notice?
1. 3 What did you do then?
1. 4 Where did you look for help/ information / treatment / didn't do anything?)
1. 5 What kind of information have you received about your child's condition?
1. 6 Who provided the information?
1. 7 What kind of treatment / rehabilitation has your child received?
1. 8 Who provided the treatment / rehabilitation?

2. The informant's perceptions of the family's attitudes, reactions and actions towards the child

- 2.1 How did your family react, when they realized that your child had a disability?
- 2.2 Did your family accept or reject the child? (Other alternatives)
- 2.3 Does your family support you in your daily living with the disabled child?

3. The informant's perception of the community's attitudes, reactions and actions towards a disabled child

- 3.1 What do people in your community think/say about a disabled child?
- 3.2 Are there positive / negative comments? (Rejection / acceptance etc.)
- 3.3 How are disabled children treated at school / at home?
- 3.4 Have you received advice / support from the community in your daily living with the disabled child? From the authorities?
- 3.5 Do you know of other families with disabled children where you live?

4. What special needs do families with disabled children have?

5. The usefulness of a local rehabilitation promoter

- 5.1 Would a local rehabilitation promoter be useful in your community? If so why?
- 5.2 What would the rehabilitation promoter need in order to do the CBR-work?

6. When very sensitive information had been given a last question was added:
How did they feel about being an informant?