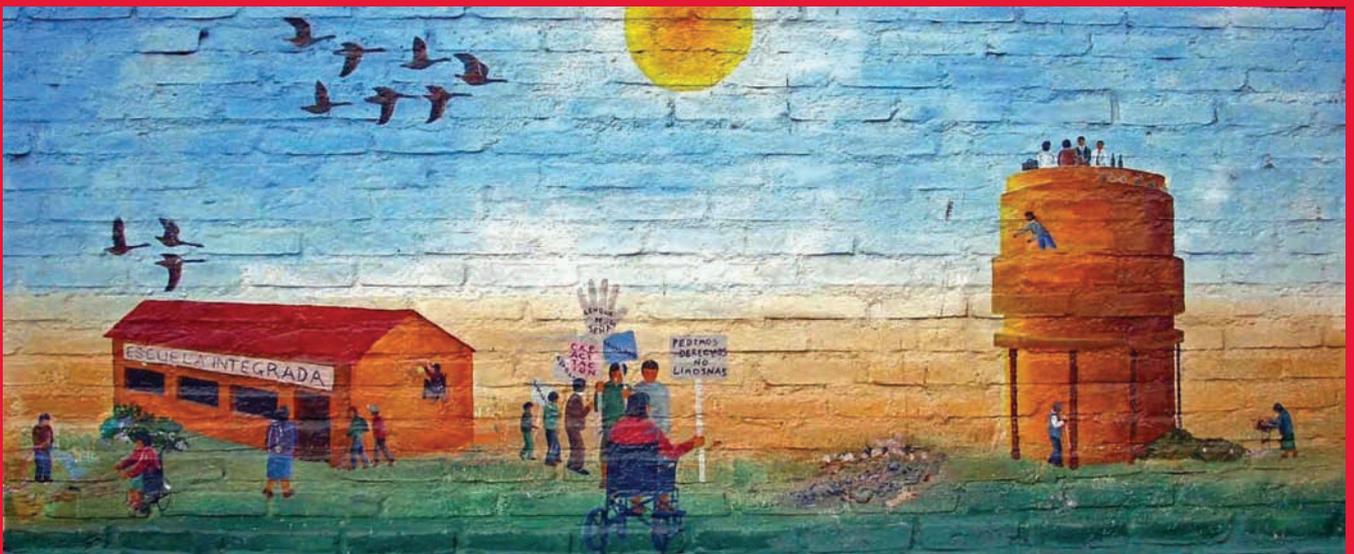


‘I don’t have a problem, the problem is theirs’

The lives and aspirations of Bolivian
disabled people in words and pictures



Rebecca Yeo and Andrew Bolton

Foreword by Bill Albert

The Disability Press
Leeds

Front cover - Photograph of mural in Santa Cruz, Bolivia: Disabled people organise to cultivate the land, create a school and campaign. Meanwhile, NGO workers sit on top of an inaccessible tower, drinking wine, with bags of money supposedly for disabled people around them.

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disabled people in words and pictures**

Rebecca Yeo and Andrew Bolton

**The Disability Press
Leeds**

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The Disability Press

The Disability Press seeks to provide an alternative outlet for work in the field of disability studies. The Disability Press acknowledges and draws inspiration from the work of all those countless disabled individuals and their allies who have, over the years struggled to put this particular issue on to the political agenda. Its establishment is a testament to the growing recognition of 'disability' as an equal opportunities and human rights issue.

The Disability Press is located in the Centre for Disability Studies and supported by the School of Sociology and Social Policy, University of Leeds.

“A disabled person finds themselves in a dark place where there is no sun. To reach the sun they have to spend days, weeks, months, years, they have to walk in whatever way they can, to pass mountains and rivers where they are not supposed to walk, and to communicate with other people. In this way they will reach a path where they find blind people, deaf people, non-disabled people and walk together, struggle together, build a country for the good of not just disabled people but also for non-disabled people, blind people, deaf people. For me everyone is equal.”
(Wheelchair user in Sucre)



“If an airport is needed, in one way or another, the government will find the money. But when the issue is poor people there is no money...The government says it is helping poor people but the reality is different. Governments do big things...People in power need incentives to see poor people...Governments want publicity after they have done some work, but they don’t receive anything for working with adults who have already been abandoned. Nobody is bothered about these people. The poorest people don’t complain...those most in need are those who speak least.” (Director of church institution for homeless people)

Preface

This report is based on research carried out in Bolivia between April - December 2006. I do not claim to cover the history or politics of the disability movement in Bolivia, only what was said to me, mainly by disabled people, during the nine month research period. This report reflects my analysis of the findings and not the views of the commissioning organisations. In fact, International Service, the principal NGO involved, has rejected my conclusions. They have produced a separate report.

Rebecca Yeo

Acknowledgements

This research was initiated by a team of two people from the British based NGO, International Service (IS), one from the Comité Nacional de Personas con Discapacidad (Conalpedis) and one from the Comité Departamental de Personas con Discapacidad (Codepedis). Two people from Sense International joined this group at a later stage. The research itself, including the mural process, was carried out by the authors of this publication: Andrew Bolton and Rebecca Yeo.

The research was funded by the British Department for International Development (DfID), International Service (IS), Wales Arts International and Sense International.

We are grateful to the many individuals and organisations that took part in this research, freely giving their time and thought to the issues involved. Many of the disabled people who took part described huge difficulties and injustice in their lives. Many also described their continual battle to challenge this situation. We hope this written report and the visual representation of the murals does justice to their struggle and contributes in any small way to building a more just society for all.

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Abbreviations

- APRECIA** - A group for the rehabilitation of people with visual impairments
- COBOPDI** - Confederación Boliviana de Personas con Discapacidad (Bolivian Confederation of Disabled People)
- CODEPEDIS** - Comité Departamental de Personas con Discapacidad (Departmental Committee of Disabled People)
- CONALPEDIS** - Comité Nacional de Personas con Discapacidad (National Committee of Disabled People)
- CONAMAQ** - Concejo Nacional de Ayllus y Mark'as del Qullasuyu (Assembly of *Ayllus* and *Mark'as* from *Qullasuyu* - a union of indigenous people)
- CPC** - Centro de Parálisis Cerebral
- CSUTCB** - Confederación Sindical Única de Trabajadores Campesinos de Bolivia (Rural Workers Labour Union of Bolivia)
- DFID** - British Government Department for International Development
- FEDEPDI** - Federación Departamental de la Persona con Discapacidad (Departmental Federation of the Disabled Person)
- FENACIEBO** - Federación Nacional de Ciegos de Bolivia
- IBC** - Instituto Boliviano de la Ceguera (Bolivian Institute for the Blind)
- IS** - International Service
- NGO** - Non-governmental organisation
- OEA** - Organización de Estados Americanos (Organisation of American States)
- POA** - Plan Operativo Anual (Government's Annual Operative Plan)
- PNIEO** - Plan Nacional de Igualdad de Equiparación de Oportunidades para las Personas Con Discapacidad / National plan for equalising opportunities for disabled people
- RIC** - Rehabilitación Integrada en la Comunidad (Rehabilitation integrated in the community)
- SEDEGES** - Servicio Departamental de Gestión Social (Departmental Social Services)
- SEDES** - Servicio Departamental de Salud (Departmental Health Services)
- SEDUCA** - Servicio Departamental de Educación (Departmental Education Services)
- UNDP** - United Nations Development Programme
- USAID** - United States Agency for International Development
- WHO** - World Health Organisation

Foreword

What you are about to read is wonderful and disturbing and virtually unique. It comes from the raw voices of disabled people. Not leaders or the conventionally articulate, but the voices of ordinary disabled people talking about their lives. And it gets better, because they have, through the creation of public murals, also painted their lives and aspirations.

I have been active in the disability movement for over 25 years and I have heard these stories. Not from people in Bolivia, but from disabled people in the UK. I have heard these stories from disabled people in Russia and Eastern Europe, as well as Africa and Asia. Everywhere the story is the same. The story is about systematic discrimination, it is about poverty, it is about the almost casual, everyday violation of disabled people's human rights. So, why do I say this is a unique report?

It is unique because I have never read this story elicited, listened to and reported in such an honest, candid and effective manner. I have never felt and seen this story told with such immense authority. It really is about people speaking truth to power.

The report is also unique because it offers a much-needed, almost forensic insight into the way NGOs operate and how, out of what may be the best motives, many have become part of the problem, not part of the solution. As you will see, this critique comes from disabled Bolivians themselves, who, among other mysteries associated with aid giving, find it hard to understand why with so many well-qualified disabled people in their own country, many NGOs insist on recruiting so-called experts from abroad.

This model of working creates resentment, made more profound because people who are poor have little choice but to accept the insult of such patronising charity and accept it with a smile. It is, after all, as one disabled Bolivian tells us, (and you can almost see the shrug of resignation) '*mejor que nada*' / 'better than nothing' (see 2.3.5). It is also the only game in town that offers substantial financial support. Unfortunately, the way the game is played does not lead to progressive or sustained change, either in Bolivia or any other part of the developing world. The principal outcomes have been to maintain the status quo, build the capacity of the NGOs, both international and domestic ones, provide an income for consultants and/or soothe the consciences of middle-class volunteers. And for poor disabled people? Almost none of the money gets through.

What is perhaps worse, is that when projects end and the 'professionals' or volunteers go home, little remains, except frustration. It is only when the aid money goes directly to those local disabled people who understand the reality of their own societies as well as their own lives and are people who will stay once the project has ended, that the capacity of disabled people and their organisations can be built and sustained. All else simply perpetuates neo-colonial relationships, which, as Bolivian disabled people tell us and show us in this report, oppress and disempower.

Bill Albert
International Disability Equality Agency, Norwich, UK
December 2007

Executive summary

This qualitative research study was designed to identify the needs and demands of disabled women, men and children in Bolivia, to discover the nature of current initiatives in the area of disability and to prioritise areas for intervention. More detailed objectives are set out in section 1.3.

The work was conducted in: Sucre, Tupiza, Santa Cruz and the province of Ingavi. The intention was to work with focus groups of disabled people living in as wide a range of situations as possible, not to obtain statistically representative samples. The use of figures and percentages is deliberately minimised in order to avoid giving a misleading impression of statistical validity. Interviews were conducted with local and national authorities and with representatives of NGOs, largely depending on the priorities and suggestions made by disabled people in focus groups. Twenty-three focus groups and 57 interviews were conducted and several meetings attended. See section 1.5 and 1.6 for discussion of methodology.

The focus groups and interviews in this research were complemented by the work of a community artist, who worked with disabled people participating in the work. He put their main messages into pictorial form and combined the ideas into a mural in each main location. Official opening ceremonies were held as the murals were completed, at which local authorities, NGOs, the media and members of the public listened to disabled people describing the messages portrayed. Photographs of these murals are included in Section 4 to illustrate the priorities expressed by disabled people. This process, which is further described in section 1.5, played a key role in the research, as well as in the expression and dissemination of the findings.

The priorities expressed by disabled people are described in section 2, followed by some different priorities expressed by non-disabled interviewees. There was frequently a large divide between the two. Disabled people in every focus group talked of discrimination as the over-riding issue, giving examples of exclusion from employment, education, training, transport and health services. In rural areas disabled people talked of their priorities as being basic needs such as food, clothing and shelter. In other places, disabled people talked of having no choice but to search through people's rubbish or to beg in order to survive. Meanwhile many non-governmental and governmental organisations focused on issues such as rehabilitation, prevention of impairments and the attitudes of families towards their disabled member. This is not to imply there was no overlap between the priorities of disabled people and the perceptions of non-disabled interviewees. Some disabled people did talk of the need for rehabilitation and some non-disabled people did talk of the problems of discrimination. But the over-riding emphasis was quite different.

Many organisations for, but not of, disabled people claim a representative role. The issue of who really represents who is considered in section 6, as are

other aspects of the different roles of organisations **for** and organisations **of** disabled people.

Disabled people are more organised in some parts of Bolivia than in others, and many advances have already been made. This report does not go into the history of these advances, only to the current situation as described by the participants. Members of focus groups suggested possible solutions to the difficulties currently experienced. These are outlined in section 8, followed by the researcher's recommendations in section 9.

It was found that several governmental and non-governmental organisations are currently running projects on behalf of disabled people. However, little of this work is led by disabled people, or based on a strategic analysis of disabled people's needs and priorities. The primary conclusion from this research is that whilst many organisations currently claim to work on behalf of disabled people, many of their actions actually distract from the fundamental changes that need to take place if the systemic discrimination is to be addressed. When an organisation says it includes or prioritises disability, this should not be automatically welcomed. There is a great need to build a disability movement strong enough to bring about the changes that disabled people themselves prioritise.

Employment of disabled people was found to be extremely low. Many, even of those NGOs specifically set up to work on disability issues, did not employ a single disabled person themselves. This calls into question the credibility of claims to focus on the capabilities of disabled people. Several interviewees attempted to justify lack of employment of disabled people by stressing the need for experts. The all-pervasive assumption was that disabled people cannot be experts, despite having 24 hour a day experience of disability and despite many being fully qualified and experienced in a profession prior to becoming disabled.

While many organisations **for** disabled people were found to have substantial sources of international and national funding, many organisations **of** disabled people do not even have a place to meet. The anger expressed towards the work of NGOs was widespread. Disabled people and some NGO members of staff (insisting on anonymity) repeatedly talked of NGOs taking advantage of disabled people, making money out of disability, or being here in order to maintain the status quo. When the leader of a local federation¹ of disabled people was asked why he thought so many NGOs work with disabled children and so few with adults, he replied, with no hesitation: "because children do not demand their rights, they are easier to take advantage of."

Some suggested steps forward emerge from this research. Most importantly disabled people need to be the protagonists of change. One disability leader talked of the need to revise the law on disability, and of how useful it would be to exchange ideas with disabled people in other parts of the world with similar

¹ Federations are groups of associations **of** disabled people; this is clearly distinct from institutions **for** disabled people.

experiences. Within Bolivia, there is a desperate need for Sign Language teachers particularly in more rural areas. There are also many unemployed deaf people who know Sign Language, generally in urban areas, and could become teachers if given the opportunities. Similarly many blind people in rural areas complained that there was no-one to teach them Braille, whilst other blind people, predominantly in urban areas, know Braille but are unemployed. Parents of deafblind people talked of wanting to become teachers themselves in order to offer their children better opportunities. They would be motivated by their personal experiences, so it would be likely that the present rapid staff turnover would be reduced. Disabled people's organisations need funding for meeting places, office equipment, and transport to enable members to come to meetings. NGOs need to question where their real allegiances lie. If they really aim to support marginalised and oppressed people then the focus should be on putting more power in the hands of disabled people themselves.

1. Introduction

1.1 Background

This research was conducted in Bolivia from April to December 2006 during the first year of Evo Morales Ayma's term as the first indigenous President of the country. It was a time of great social change and uncertainty, as has been much of Bolivia's recent history:

- May 1st - nationalisation of the country's gas supplies was announced;
- July 2nd - elections for the assembly that would re-write the constitution. The *Movimiento al Socialismo* (MAS) won an absolute majority but not the 2/3 necessary to pass changes to the constitution alone. A referendum on autonomy for departments/states was held on the same day in which, broadly speaking, eastern, more prosperous, departments voted for autonomy, and the western departments voted against it;
- July - congress to discuss educational reform. A proposed bill to transform what the education minister referred to as a neo-colonial system into one where children learn about indigenous culture in their own languages, led to protests and the congress collapsed;
- August 6th - Bolivian Independence Day, inauguration of the new constituent assembly.

On the first anniversary of his Presidency, Evo Morales referred to the Bolivian process as a democratic cultural revolution "integrated on four fronts: executive, legislative, social movements and the constituent assembly". Underlying this government's approach is the determination to change a system based on neo-liberalism and foreign control of the country's resources. This is in the face of vociferous opposition, particularly from those in the eastern half of the country, demanding autonomy. Most recent governments allied themselves with the United States and its supporters; instead, President Evo Morales Ayma has focussed on alliances with left-leaning governments, particularly President Chavez in Venezuela, and President Castro in Cuba. Together they formed the *Tratado de Comercio de los Pueblos* in May 2006, as an alternative to the free trade agreements offered by the US.

Ramiro Delgado from the *Vice Ministerio de Co-ordinacion con los Movimientos Sociales*, part of the Ministry of Government, described how this government "is the product of social organizations". He went on to say that the aim of this government is:

"The construction of participative, democratic public policies. Until now public policy was made from above, now we want to build policies from below with different civil society organisations and social movements... Together with these organisations we want to build inclusive public policies".

1.2 Disability context

The situation of disabled people at this time must be seen within the above context. It is beyond the scope of this research to describe the history of the disability movement in detail, however a brief summary is necessary in order to understand the current situation.

Strong and persistent campaigning in recent years led to several changes. The Disability Law 1678 was passed in 1995. One component of this was the establishment of the National Committee of the Disabled Person (Conalpedis) and the Departmental Committees of the Disabled Person (Codepedis) in each region (department). The main objective of these public institutions is “the orientation, coordination, control and advice regarding policies and actions to benefit disabled people”. Neither Conalpedis nor Codepedis are organisations **of** disabled people. They are each composed of a board of directors with eight members. Half these members are elected at a congress of disabled people. The other four are made up of a representative from the Ministries of Education, Health and Labour and representative from NGOs working on disability issues. The only paid employee that has to be a disabled person is the director. In some departments this person is the only disabled employee. These institutions are considered in more detail in section 6.3.1.

Disabled people campaigned successfully for law 1678 – (see full mural Tupiza 4.2.4).



In April 2006, the current Government passed *Decreto Supremo 28671*, establishing as public policy the National Plan of Equality and Equity of Opportunities for Disabled People (PNIEO). The overall aim of this plan is the ‘enforcement and full exercise of disabled people’s rights’.

Disability representatives have been appointed within several Government ministries. The newly formed Vice Ministry of Coordination with Social Movements also has a representative with a strong background of working

with the disability sector. However, non-disabled people were appointed to all these posts. A blind person was appointed on a temporary contract basis within the Ministry of Planning.

The current Government was elected on a strong platform of inclusion of the indigenous majority. Inclusion of disabled people could be seen as a natural component of this approach. As Ramiro Delgado described his work:

“We have meetings of social organisations that make demands. What we do is we analyse these demands and pass them on, as appropriate. For example, we are talking about disabled people. They come and ask for work, and lots of things related to the law and its flaws. What we do is we analyse these demands, and, as it has to do with work, we send them to the Ministry of Work...”

The extent to which disabled people are, in reality, effectively included in Government work will be considered later. This research found several weaknesses in both the law and the state institutions, but this is not to underestimate the serious and successful campaigning that achieved them.

1.3 Definition

The definition of disability in the law 1678 is “all restriction or absence, due to a deficiency, of the capacity to carry out an activity in the manner, or within the margin of what is considered normal for a human being”. As it is the official definition used in Bolivia, it is used by those disabled people more aware of national policies. It is not a definition that the authors of this report feel comfortable with, implying as it does that normality exists and that there is something wrong with disabled people. This research process accepted the definitions used by participants.

1.4 Objectives of the original research

To propose strategic lines of action, based on the problems and identified demands, to organisations and institutions, both national and international, that work in inclusive development, in order to make an impact on public and private policies that will benefit disabled people in a real and effective way, allowing the achievement of attaining a dignified life and equality of opportunities.

Specific Objectives:

- To identify the needs and demands of disabled women, men and children.
- To discover the current work of national and international institutions, both public and private, in the area of disability.
- To prioritise areas of intervention that are not being taken into account in an efficient way, for institutions that work in the area of disability.
- To determine and propose effective work methods that will contribute to a strategic impact in both the institutional and organisational action.

1.5 Methodology

Before detailing the results of this research, the scope and the limitations of the process should be recognised. This research was conducted in a qualitative manner; no statistical assumptions should therefore be made from the results. The sample is purposive not representative: the intention was to include disabled people living in as wide a range of situations as possible, not to reflect the prevalence of these situations. Twenty-three focus groups and 57 interviews were conducted and several meetings were attended². With a few exceptions, focus groups were conducted with disabled people and individual interviews with representatives of local or national authorities and NGOs. The preference for focus groups of disabled people was designed to encourage the exchange of ideas, and to reduce the effects of the power imbalance between a white, rich (in economic terms) researcher and predominantly poor (in economic terms) Bolivian disabled people. In individual interviews, respondents are more likely to try to please the interviewer. Individual interviews were carried out with authorities and NGOs where the power imbalance between interviewees and the researcher was not felt to be so strong or influential.

The departments included in the study were Potosí, Chuquisaca, La Paz, and Santa Cruz. The intention was to take the geographical diversity of Bolivian regions into consideration – including high plains, low lands and the valleys. Within these regions, focus groups included disabled men, women and children living in urban and rural areas; people living with their families and those living in institutions whether specifically for disabled people or more general, such as prisons and old people's homes; people recently disabled and those disabled for most or all of their lives; people with genetic impairments and those injured through illness or accidents, whether medical, traffic or industrial, particularly in mines; people with financial support (few participants were employed) and those forced to beg or scavenge through rubbish to meet their basic needs; people heavily involved in the disability movement and people not even aware of the existence of disabled people's organisations; people with any form of impairment whether physical, visual, hearing, deafblind, psychological, or multiple impairments. The agenda for interviews with representatives of NGOs, government agencies, human rights groups and others was strongly influenced by the priorities expressed by disabled participants in focus groups. See annex for a full list of focus groups and interviews.

Participants in focus groups, with the help of a public artist, put their key messages in the form of drawings that were then combined into murals. The murals were painted in prominent public places in each of the main areas of work: Sucre, Santa Cruz, Tupiza, and Tiahuanacu. A mural opening ceremony was held at which local authorities, NGOs, the media and the general public listened to disabled people describing the messages portrayed in the murals. Local authorities were also invited to address these meetings,

² A full list of focus groups and interviews is included in the annex.

partly in order to ensure that they give the issues at least enough consideration to prepare a speech.

A photographic exhibition of all the murals was held at the Casa de Cultura in La Paz at the end of the research process. National and local government departments, NGOs, organisations of disabled people and the media were specifically invited to the opening of this exhibition. There, disabled people who had been involved in the making of the murals, explained their main messages. The exhibition was open to the public for 10 days. See section 4 for descriptions and photographs of the murals.

1.6 Difficulties with the research process

The research process was hindered by the inherent inequality of white employees of a well-financed NGO extracting information from Bolivian disabled people in need of resources. The assumption that, if the right things were said, resources would follow, could have been reduced had a visibly disabled Bolivian been employed instead. On several occasions, participants asked what they needed to say in order to get funding.

It is inevitable in NGO consultations that people in need of resources will say what they think necessary to get resources. For this reason, at the start of each group, it was made clear that resources were not linked to this research, whatever participants said, and that comments would be made anonymous unless specifically agreed with the participant. All participants freely gave their time and ideas. The leader of the *mallku* (indigenous leaders) in one community was reluctant to invite disabled people to take part, once he heard there were no immediate material benefits to offer. He talked of other occasions when NGOs had come to extract information out of people who had gained nothing from the process. In many areas there was wariness that, as employees of an international NGO, the researchers were there to take advantage of disabled people.

At a preliminary meeting introducing this research to an organisation of disabled people, several people were angry that apparently non-disabled foreigners had been employed rather than local disabled people³. There is very high unemployment amongst disabled people and as one person put it, they are sick of foreigners coming thinking they will come and 'help' Bolivians. The aim of the organisation setting up this research is to 'act in response to local requests for skills that are not available in the region'...they provide human resources from industrialised countries to 'share their skills and experiences with the local people to strengthen their efforts to improve their situation'⁴. A highly educated disabled person said the notion that there are not local people with the relevant skills 'makes me furious'. Since this research finished, this organisation has begun employing a disabled Bolivian professional.

³ Whilst both the researcher and the artist involved in this project have personal experience of disability, neither has a visible impairment.

⁴ See <http://www.internationalservice.org.uk>

If a local disabled person had been contracted to lead this research, they would have had a higher degree of understanding of the historical and cultural context; language barriers would have been reduced (although it is unlikely that any one person would speak the full range of languages spoken in Bolivia); and perhaps most importantly, there would have been a strong intrinsic message of the expertise of local disabled people. As it was, this research process could be accused of exacerbating the widespread notion that white Europeans are more expert than local disabled people. This was particularly a problem when interviewing members of local or national authorities who, on several occasions, asked the researcher what to do for local disabled people, as if this were better than asking disabled people themselves.

Whilst there were specific attempts to contact people who would not normally put themselves forward, there is likely to be some bias in this research towards more confident, articulate and organised disabled people. It is inevitably more difficult to find the most isolated people. In rural areas where mobility is a major problem, and where there are no disabled people's organisations, it was particularly hard to find disabled people. In these areas, it is likely that more disabled people are hidden in their homes and there is more shame associated with disability. The researcher had to ask others how to contact local disabled people, or to approach visibly disabled people and invite them to take part. This made the work biased towards those with visible impairments and inevitably involved some level of coercion. The power difference means that only a very self-confident person would refuse the invitation. Self confidence is not a trait often linked to being among the most marginalised. If an obviously disabled Bolivian person had been conducting the research, people might have felt less pressured.

On the other hand, there were also some advantages to the researcher being an outsider. Not having career prospects to consider gave the freedom to report what was said rather than what those with resources might like to hear. A further possible advantage of not being a regular employee of an organisation in Bolivia may be that respondents were more open with their criticisms. On numerous occasions, people expressed strong anger at the actions of NGOs. Perhaps these would not have been said had they been perceived as clearly personal. There was marked reluctance to repeat these criticisms in public forums such as the mural inauguration ceremonies.

The intention of the researcher was to allow the process itself to be partially determined by the priorities of the participants, and to be a tool in their work for change. Research can all too easily become an alternative to, rather than part of, a process of change: it can use up large amounts of resources, entrench existing power relations, and merely reiterate what was already widely known.

One difficulty was that people rarely turned up together or on time, so groups were often interrupted as more people arrived. This made it difficult to repeatedly explain the context to newcomers. But it was also difficult to turn

people away, as they had often made big efforts to get to the venue. Similarly, although the researcher preferred to work with groups of between 8-10 people, this was rarely controllable. On one occasion approximately 40 people arrived. It was felt that it was better to work with the group that was there, rather than to turn people away.

Participants of focus groups helped determine who to interview and with what specific aims. People were also offered paid work helping with interviews where possible. The latter had limited success. To make this more effective, more time would have been needed to build confidence and interviewing skills. As it was, people often did not turn up, or arrived so late that there was no time to discuss techniques or purpose. On one occasion, having had only a short time to plan some strategic issues, the first question that a local disabled leader asked when interviewing a local authority was whether a vehicle could be supplied for the researcher. This was followed by asking for a pension for disabled people. This leader of a local federation of disabled people had very little opportunity to access local authorities, and therefore tried to use the opportunity for purposes beyond the research needs. There was clearly insufficient understanding of the potential for this local authority to act.

A group of representatives from International Service, Sense International, Conalpedis and Codepedis were responsible for overseeing the work of the researcher and artist. Two of the six members of the group were disabled, one representing Conalpedis and one Codepedis. During the research process, there was ongoing conflict between Codepedis and organisations of disabled people. On many occasions it was felt important for the researcher to show some distance from these agencies in order to get involvement from organisations of disabled people.

2. Priorities emerging from focus groups of disabled people

2.1 Existing situation and priorities for change

All focus groups of disabled people were asked what their main priorities were. There was a noticeable difference between the needs expressed by the poorest, most isolated, disabled people in rural areas, and those slightly better off in more urban areas. Discrimination was seen as the over-riding issue, and the cause of most problems among all groups irrespective of age, gender, location, impairment or economic status. Disabled people in all areas talked of their struggle to get equality. Examples of current inequality varied from one group to another. People in slightly more advantaged areas then spoke of the need for work, education or training for employment. In rural areas priorities were expressed more directly in terms of basic needs such as food, clothing and shelter. Many people in these areas seemed to have considerably lower ambitions in terms of access to equal opportunities. Whilst the association of disabled people in Tupiza repeatedly mentioned the need for food and clothing, people in an association of deaf people in Sucre talked of the need for deaf schoolteachers who use Sign Language to enable deaf people to have equal access to education. In more rural areas, many deaf people were not aware of the existence of Sign Language.

Considerable difference was found between levels of organisation of disabled people in different areas of the research. In Santa Cruz, where the local Federation is stronger than in most parts, people described how their persistent demonstrations have at least resulted in some employment of disabled people in the town hall and in the local electricity company. There was also notably more talk of the needs of disabled people among local authorities in this area.

In all areas, people mentioned the need for accessible healthcare and transport. Only occasionally did issues of rehabilitation and prevention come up as priorities in focus groups, but these issues were often focussed on by non-disabled people. Lack of physical access seems to be widely accepted as part of life, for example wheelchair users routinely get carried into buildings (see photographs section 2.9).

Leaders of the Confederacion Boliviana de Personas con Discapacidad (Cobopdi) spoke of the need to exchange information and experiences between disabled people's organisations around the country and even the world. People spoke of the need to revise the current law on disability. They said it was important to exchange information with disabled people in different countries who have been involved in drafting civil rights legislation for disabled people.

Lack of self-esteem and confidence were mentioned sometimes as the main cause of the disadvantages faced by disabled people. Some disabled people blamed other disabled people for limiting themselves with their own self-pity.

In urban areas, NGOs were repeatedly criticised for taking advantage of disabled people in order to get funding whilst doing nothing to address their priorities. In more isolated areas, NGOs were rarely mentioned. Many disabled people in these areas seemed unaware of the existence of NGOs. Whilst there are many different kinds of NGOs working in Bolivia, very rarely did disabled people make any distinction between them.

The main priorities mentioned in focus groups will now be examined in greater detail.

2.2 Discrimination

Discrimination was repeatedly mentioned as the root cause of lack of access to work, health care, education and of social isolation.

Such discrimination was referred to in every focus group of disabled people, no matter which gender, geographical region, type of impairment or socio-economic status. In contrast, in many interviews of non-disabled people, there was pronounced lack of awareness of the existence of such discrimination. Several members of staff of NGOs, even among those that work with disabled people, seemed shocked by each example of discrimination that they came across, as if each were a separate and new obscenity. On the other hand, disabled people in focus groups talked of discrimination as a matter-of-fact part of daily life.

The manager of the network of health professionals in Tupiza reported that, “there is no discrimination”, - then again that, “there is no social discrimination against disabled people”. After further probing he added, “at least I have never seen any discrimination”. However, just a few metres from this person's office, disabled people in focus groups reported, “there is discrimination in every aspect”, “I would say to the population that they should take us into account, that they shouldn't discriminate against us”. Parents of disabled children spoke of the urgent need to teach non-disabled children and teachers not to discriminate, “we need to tell society not to discriminate against us” (see section 2.4.1 for more examples of the discrimination faced by disabled children in schools).

Younger children seem less aware of discrimination. In focus groups of children, only those over the age of approximately 15 talked of discrimination. They talked of how hard it was when they realized they were treated differently. One teenager said when he was younger, “I thought I was the same as other people, I didn't realize there was a difference”. Another person said, “children don't know that they are disabled”.

People's designs for the murals contained references to discrimination in every location (see section 4). Some of the comments made include:

- "Non-disabled people discriminate against us";
- "They look at us as if we were strange creatures";
- "The most healthy⁵ people are the worst people";
- "One feels totally rejected. It is as if deafblindness were an infectious disease";
- "I wish people would not look badly on me";
- "Everywhere they discriminate. In the street they don't give you space, in the way they reply to us";
- "In the street strangers bully me, they hit me";
- "Neighbours hit me with sticks. They don't help me. Some hate me. They want me to disappear. It's been like that all my life";
- "They hit me...I don't like it that they bully me";
- "Institutions don't take us into account";
- "If only they would take us into account";
- "Often they don't think we are capable. Non-disabled people discriminate against us, they think we can't do anything";
- "Many people say to me, you won't be able to do anything";
- "We don't have opportunities";
- "They don't open the door to us, we suffer discrimination, we are isolated from society, they don't take us into account as human beings";
- "There is a lot of discrimination in society";
- "Even in the family we suffer this discrimination";
- "Sometimes, when a disabled person goes to a meeting, people don't value the disabled person and don't take that person into account and I say that they have to take them into account";
- "If only they wouldn't close doors to us";
- "The environment is hostile, because all the time you are undervalued";
- "There is lots of discrimination";
- "Because we are like this, other people keep a distance from us";
- "Because of this little accident from now on I have first hand experience of discrimination";
- "Everywhere disabled people are discriminated against".

Some groups mentioned different levels of discrimination depending on types of impairment. A participant in a group of deafblind people in Santa Cruz reported, "there is more tolerance of some impairments". A group of people with physical impairments considered that they face the worst discrimination and blind people the least. Blind people perceived the opposite. Several people in different groups considered that discrimination is worse depending on the degree to which someone "can't defend themselves" and that there is, "a lot of discrimination against people with mental disability" or that "we are discriminated against the same whether we are blind or have a wheelchair. But those with learning difficulties suffer the worst discrimination". Whereas a group of people who would commonly be regarded as having learning

⁵ Literally translated, but used to mean non-disabled

difficulties looked at a picture of a wheelchair user and said it must be harder for her than for themselves. It was unclear from this group whether they actually perceived themselves to be disabled or not.

One of the issues for deafblind people is that they often use touch and smell to recognize people. This can cause hostility among strangers. The parents of a 21-year-old deafblind person remarked, “what really hurts her is that no-one in society accepts her”. Similarly, the sister of a deafblind person noted that, “society doesn’t accept her...they don’t want to get to know her”.

Fe y Alegria, a Christian NGO working predominantly on education projects in several South American countries, recognised discrimination as a major problem and started a six-months awareness raising campaign of TV, radio, and press advertisements at the end of 2006. Staff had become aware that focussing on education is insufficient if people have no opportunities when they leave school. However, the nature of this campaign was severely criticised by some disabled people. The TV advertisements depicted disabled people as heroes, not as ordinary people with ordinary needs: one depicted a non-disabled person singing very out of tune, followed by a blind person singing beautifully; another showed an over-weight man running slowly, compared with someone with Downs syndrome running fast. The Ministry of Education also recognised the need to address discrimination and started an awareness-raising campaign at the end of 2006 (see section 2.4.1 for more discussion of this). Many non-disabled people spoke of the family as the prime source of discrimination, (see section 3.3) with little mention of the wider discrimination that families respond to.

Discrimination was referred to by disabled people as the root cause of lack of access to the other priorities outlined below:

2.3 Employment and work

Lack of employment was frequently mentioned as a major priority, both by focus groups of disabled people and in interviews of non-disabled staff of NGOs and authorities.

2.3.1 General employment situation

It has been acknowledged that the sample of disabled people in this research is likely to be biased towards the less marginalised and more confident. Despite this, few participants had any form of regular income. Of those that did, most worked for themselves whether this was begging, scavenging, or selling things in the street. Many also worked without pay in the home, caring for other members of the family (for example a partially sighted grandmother looked after her disabled grandson near Tiahuanacu) or helping in the family business. Many parents of disabled children in particular reported needing to find waged work in order to support the family financially, but this was in conflict with the need to give care and attention to the child: “Often I have to leave the children on their own while I go and work”. Recognition of the unpaid work caring for others was called for.

Several participants in this research reported having a choice between begging and scavenging through rubbish for anything usable, collecting cardboard, bottles and tins to sell for recycling (see Section 4.2.5 for a depiction of this in the Santa Cruz mural). Those doing the latter described the reality of this work:

“There is a rich house where they throw lots of bottles away. But rich people protect their rubbish. The guards don’t let you look. One guard comes. The drug addicts and other people who live in the street run faster than disabled people. One woman hit me.”

As one person put it, “the majority of disabled people beg”. One participant described how his friend injured his foot, but that:

“There’s no money to go to the doctor. He goes to the markets and avenues with his crutches to beg. It’s hard for him to go out on foot, and sometimes he comes back with nothing”.

Several people who talked about begging themselves were very ashamed and upset by it, “I’m ashamed of begging for help, I’m tired of that”, but the reality is that for many disabled people there is currently no alternative.

The situation could be described as a vicious circle: lack of formal training opportunities, combined with discrimination in the workplace, leads to few disabled people having much work experience. But many employers use this as an excuse to not employ disabled people. Even among the relatively small sample in this research, there were many highly trained people:

“Among us there are teachers, accountants, solicitors, our defects don’t make us worth less, we are as capable as others. If we do something wrong we can be judged just like anyone else. If we have done something wrong... but just because we are disabled they don’t give us work”.

Many interviewees did not seem to feel the need to give any justification for not employing disabled people. Responses included: “disabled people can’t work here” or “no disabled person works here because it’s not made for that. What we need are cooks, people to do the washing and to make the beds”. The unquestioning assumption being that disabled people could not do any of these things.

One man who lost his sight in a rural area near Tupiza talked of how his teaching hours have been progressively cut as his sight has diminished. On this occasion there may be some hope for him: a church organisation is planning to start a school for disabled children, and recognises the importance of employing disabled teachers within this. In contrast to this, a large NGO specifically for blind people is recruiting more people to train as teachers, but would not train blind people itself.

Lack of access to employment opportunities was a strong theme in focus groups and mural designs in all areas where the research was conducted. See section 4.2.4 for photographs of Tupiza mural (graffiti calling for employment) and 6.2 for people campaigning for work in Santa Cruz mural.

Some examples of people's comments are:

Santa Cruz:

- "Everything is lacking, even access to work";
- "The biggest problem is lack of employment";
- "The important thing is work, with that we would have more freedom for our families. Without work and without money our situation can't change";
- "The first thing is work for all the disabled";
- "There is no work in the town hall and it's even worse elsewhere";
- "Just because we are disabled people we aren't given opportunities to work";
- "...the need for work";
- "To get work, that would mean to get money";
- "This is happening in all the special centres...for example in Santa Cruz there is the centre Teresa de los Andes. All the workers there are non-disabled yet they say it's for disabled people. Why don't they at least employ a disabled porter?"
- "For many people it's difficult to get out of this depression, sometimes it takes a year, or two years, sometimes much more, until at last one day they can overcome it. But, when they overcome the depression, there still isn't any opportunity, there's no work".

Sucre:

- "Work is the most important thing";
- "One compañero is an agricultural engineer and a very good one, he doesn't have an arm...I said to him look my brother I'll help you find work. He did a fantastic presentation. But they laughed at him when we were leaving...they guffawed and I wanted to go back in and punch them, I was so furious, in the end I went down the steps wanting to cry, it was a terrible blow";
- "Sometimes physically we are lesser, but mentally we are equal to them";
- "The priority is lack of employment, support in the theme of employment".

Potosi

- "We want to serve society. We want to work to earn our bread. We don't want to be the rubbish of the people";
- "There are economic difficulties. We need training. We don't have work and because of that we don't have money. We don't have work because we are the least sought after people";
- "I want work - nothing else";
- "I need some capital in order to work";

- “We can do anything like anyone else, all that’s lacking is the opportunity”;
- “Lack of work”;
- “I work in the square polishing shoes and I provide for my family in this way, I don’t have any form of help”;
- “I’m looked after through my father, nothing else”;
- “No blind person has work here, although there is a blind man in the market who people pay to pray for them”.
- “No visually impaired person has work here. We all survive waiting for the annual grant of 3.300 Bs that we receive”;
- “They always give work to those that can see, those that see always get work”;
- “Discrimination is worst in work places”;
- “I studied to be a secretary when I was 25-30 years old. I presented my certificate so that they would consider me, I took an exam and came second, but the person who came fourth got the job. So they don’t take us into account. For that reason I started to work for myself... I work independently, I started it myself with my own initiative”.

Guaqui

- “We want work – to find ways of surviving”;
- “I would like the opportunity to work”.

2.3.2 Employment in national government

Under the Bolivian disability law, at least 4% of any public agency, including government ministries, should be disabled people. However, in this research no government ministries were found that actually did this. Furthermore, there were several stories of people being classified as disabled in order to increase the numbers, but who were actually ill rather than disabled.

The government now employs people responsible for disability in the Ministries of Health, Justice and Education. At the time of this research, even among these employees, none were disabled. A disabled person is employed on a contract basis in the Ministry of Planning, but is not a regular employee. The Ministry of Education has a department of ‘educación especial’, which employs three people, none of whom is disabled. At the time of interview, the Ministry was planning to train more teachers to work specifically with disabled people. When asked if this would involve training disabled people to be employed as teachers, the answer was no, “the training is for anyone, doesn’t have to be a disabled person”. The Director of ‘*educación especial*’ then said they would be trying to recruit more young people, because “young people are more dynamic and stronger”. She reported that in Brazil “they don’t let teachers older than 45 work with disabled people” She would like this also to apply in Bolivia. The age of employees is important to her, but personal experience of disability is not.

This lack of employment of disabled people is despite the fact that when disabled people come to the Ministerio de Gobierno, they are reported to ask

for, “Work. Normally work. Work and also food”. When questioned about the lack of employment of disabled people in the government, one employee responsible for disability justified the appointment of non-disabled people by saying, “it needs to be a well-informed person”

There seems to be a widespread assumption that a non-disabled person would necessarily be better informed than someone with personal direct experience of disability 24 hours a day.

2.3.3 Employment in public organisations and local government

Few public organisations employ the 4% disabled people that they are required to do by law, let alone the 10% that would approximately represent the numbers of disabled people that exist in society. Conalpedis and Codepedis are public organisations specifically set up to help implement the law on disability. But in some branches of Codepedis the only disabled employee is the obligatory director.

It was difficult to find out the exact numbers of disabled people employed in any of the public offices where interviews were carried out. It seems records are often not kept despite the legal requirement. In Tupiza there are two disabled people, out of 100 people working in the town hall. One person is employed half time, on half the minimum wage, to look after the town square. The other person looks after a public toilet. The Mayor reports the employment as “a help”. In neither case is the work seen as requiring skill or responsibility. No disabled people have yet been offered the chance to get training or employment in better-paid, more responsible work. Furthermore the contracts are currently short-term, with no guarantees or indication of whether they will be renewed. The Mayor reported that permanent contracts could not be given as this would give the employees rights, which the local administration may not have resources to maintain. The Mayor pointed out that this situation is better than in other organisations, “there is no other organisation that I know of in Tupiza that gives work to disabled people”.

In Sucre, a representative from the town hall admitted that few disabled people are employed there, but went on to say that he did not believe employing disabled people was the answer. Even if they were to employ 20 disabled people in the town hall, it would not end discrimination. In his view, the priority is to educate families to stop discriminating against disabled members (see section 3.3).

The *defensor del pueblo* in Sucre reported having tried to recruit more disabled people. Out of seven employees, none is disabled. There was recently a vacant post of secretary. As the organisation has worked with Codepedis for the past four years, staff had hoped a disabled person would apply but no-one did. It is unclear what the barriers to employment are in this example. It could be speculated that perhaps disabled people were unaware of the vacancy, or that disabled people lacked the qualifications or the confidence to put themselves forward, or that disabled people did not have

access to transport or mobility aids in order to get to the office, or that the office was not perceived as welcoming disabled people.

2.3.4 Employment in non-governmental organisations (NGOs) working on disability issues (see also next section)

Of the 24 NGOs that took part in this research, 15 either specifically work on disability issues or prioritise disability within their work. Of these 15, none employ more than one or two disabled people at most and these are generally in low paid positions. One disabled person working in an NGO was very critical of the sector, but said that sometimes we have to do things that we do not like, sometimes there is no choice. Some NGOs have occupational therapy or sheltered workshops where disabled people work, but are paid training allowances far below the minimum wage. Many in these organisations spoke of lack of employment as the biggest problem facing disabled people: “The problem for disabled people is that there are no employment opportunities”; “the biggest problem for blind people is that there is no work”. Yet, at the same time, many interviewees from these organisations were clearly shocked at the notion that they might employ disabled staff themselves. Responses included the director of an organisation for blind people getting angry and asking how blind adults “...could teach blind children to orientate themselves? Are you saying that we should employ blind people as surgeons?” As the organisation does not employ surgeons, this question was clearly rhetorical. The reality is that these institutions are doing nothing to contribute towards tackling what they themselves recognise as the biggest problem facing disabled people - lack of employment. Furthermore, children are being brought up in institutions like this one where there are no adult role models with their impairment. When referring to their plans to set up a project specifically for disabled people, one director of an NGO said, “disabled people can participate but we have to give the employment to specialists”. Once again, the idea that disabled people could be the specialists is not considered.

In another organisation, the director talked of the importance of recognising the social needs of disabled people. She talked of how she used to work in “a welfarist model”, but she then realised the importance of seeing “the ability not the disability”. She also referred to the need for “integration in the labour market”. This organisation works with children to make them “productive in society”. The credibility of these aims and of these assertions is clearly limited by the fact that none of the five employees are disabled and that they are taking no action to start employing disabled people. This organisation is in the process of acquiring more international support.

Similarly, a Bolivian organisation working on Community Based Rehabilitation only employs one disabled person. A member of staff gave a long talk about the injustice disabled people face. She even reported a study done in Cochabamba by the *Secretaria de trabajo*, which found that 40/100 non-disabled people compared with 1/750 disabled people have work. Yet she saw no contradiction in justifying their low employment of disabled people, by saying, it is because they need ‘*tecnicos*’. There seems to be an assumption

that if disabled people were to be employed it would be by random selection rather than looking for disabled '*tecnicos*'. The skills, understanding and experience gained by someone who has direct personal experience of disability appear to be totally disregarded.

Members of the association of disabled people in Montero reported that the local school for disabled children does not employ a single disabled person. They claim that the director, "defends her property like a lion defends its guard, because she lives from this. This is happening in all parts, in all the special centres ...they all work with non-disabled people"

A former employee of an NGO working with disabled people noted, "it is paradoxical that NGOs that work with disabled people do not employ a single disabled person. In the NGO where I worked there were 20 employees but not a single disabled person."

2.3.5 Employment in mainstream NGOs

Several mainstream NGOs that were interviewed claim to have a policy of including disabled people, some even claim to prioritise disability. One such international NGO does not support a single disabled people's organisation, does not employ any disabled people, does not have accessible offices and has no material in Braille, for example. The employment policy is not to discriminate against disabled people. Yet the organisational insurance policy does not cover pre-existing conditions, therefore disabled people have to take full responsibility for any financial costs associated with their impairment. Furthermore, their actual work is to bring supposed experts from other countries to support Bolivian organisations. The director of one such Bolivian organisation pointed out that at least three local people could be employed for the price of the one foreigner they were to receive. Despite all these reservations, the director of this Bolivian organisation said that, as funding for local disabled people was not on offer, a non-disabled foreigner was probably "better than nothing". But this person went on to point out how much better it would be to have funding to employ local disabled people who have 24 hour a day personal experience of the context in which they are working; employing them would at least be a contribution towards reducing the high rates of unemployment and, perhaps most importantly, it would give a message to other organisations of the value and employability of local disabled people. The credibility of any attempt to influence other organisations is severely limited if the influencing organisation itself does not employ local disabled people.

On many occasions, people taking part in this research assumed that Britain, where the researcher comes from, is somehow more advanced than Bolivia in terms of disability. The researcher had to explain repeatedly that there are many countries where the disability movement is more advanced than in Britain. If NGOs are to employ foreigners to send to Bolivia, there could at least be a more useful exchange of experiences between disabled people from countries with more advanced disability movements but with similar economic status to Bolivia.

2.3.6 Employment in commercial enterprises

Few commercial enterprises employ disabled people. There is no legal obligation to do so and, as one disabled person pointed out, “companies don’t want to employ disabled people because they are looking for profits and many disabled people are not as productive as other people”. Another person elaborated on this, explaining that the problem stems from the global capitalist system that needs ‘perfect’ people who can work fast in order to keep the cost of the final product down. People who cannot work fast enough are not valued. This analysis is borne out by the research conducted in mining organisations.

The *Federacion de Sindicatos de Mineros* says small companies and cooperatives are the worst for accidents. As it is hard for them to compete with the bigger companies, they have no money to invest in safety equipment. In the co-operatives, the workers themselves have to buy the equipment, and they often cut corners. Representatives of a federation of co-operatives agree that there are many people disabled from mining, whether from accidents, rheumatism or lung disease such as silicosis or TB. But people disabled in cooperative mines get support from the insurance and from fellow workers in a way that, according to them, often does not happen in private companies. Sometimes disabled people are able to carry on working, albeit more slowly. As they only get paid for the minerals they extract, no-one will stop them from working. Sometimes they work in groups and support one another, sharing out their earnings. If a person has to stop working they will get a pension of Bs120-450 (approximately US\$15-60 at time of research) a month depending on the level of injury. In some ways, the situation in co-ops is more precarious, as the wages paid to workers are more directly related to the fluctuating international price of minerals. Also, co-ops have in many cases taken over mines that were considered unprofitable by the private companies. For the people who work there, these mines may still be better than nothing.

Since May 1st 2006, miners legally have to be insured and to have a contract. Before that, the law allowed companies to employ workers for 90 days, then re-employ them a few days later. Under this short-term employment the employees had few rights. Even now, despite their legal obligation, many smaller private companies have no insurance. Their aim is to make a profit. Labour, health and safety and insurance are all production costs to be kept to a minimum. People interviewed in one mine reported only having been allowed three days off after their accidents, then they were told their wages would be cut if they did not get back to work. Many people complained that the company does not issue good safety equipment. A person with a head injury blamed the weak plastic helmet that the company provided.

When there is an accident and someone is injured, one worker reported that, “the bosses discard them like an old machine”. The inspector of works spoke of numerous examples of people who became disabled through their work in the mines. They come to her only when they have given up on getting compensation from the company. Many rumours were reported of companies

paying bribes to ensure that the disabled worker does not report the accident or the lack of insurance.

One worker reported that the company boss often pays the injured person a small amount, not even enough “to last for a year”. Then the disabled person goes back to their community and becomes dependent on their family. There is no point in staying in a mining community if they are unable to work in the mines. From then on, “either from shame or because they cannot walk, they do not go out. They stay in their communities. It’s difficult to find them”. Few people report the accident, they are unsure of their legal rights, they are told the accident was their own fault, they are often uninsured, have no identity card, “there’s no information, they are isolated”, often they do not even go to a health centre as they have no money or insurance to pay for treatment. Instead, “they let themselves heal at home”.

The inspector of works reported that, “many companies work on the margins of the law. They do not have health insurance. They take the person who had an accident to find medical help in health centres in other parts so that there is no evidence of the accident.” The company promises the worker that they will get their needs met as long as they do not say the name of the mine when they go to the health centre.

Mining is notoriously dangerous and inherently unsustainable work. The practice continues and, because there are few other options, workers do not refuse poor working conditions. In many parts, mining has diverted water supplies and the land has become contaminated by heavy metals, so that cultivation is impossible. When the minerals and the water supply run out, many people migrate from these areas, but until then, they accept the dangerous working practices.

2.4 Education and training

Closely related to lack of work and employment is access to education and training. Many disabled people referred to the need for training in employable skills. Some employers claim that the lack of disabled employees is due to the shortage of disabled people with relevant skills. This may have some truth in it, although it is not the full story. Many highly trained people who later become disabled, then become unemployed. Yet the experiences acquired through being disabled would be very relevant to any organisation genuinely wanting to improve the lives of the most marginalised. According to one non-disabled observer, “disabled people have not had opportunities to study... for that reason there is not management capability, they haven’t had the opportunity to develop abilities in these areas, here we have a big limitation”. Whether or not this is actually the cause of the limitations, it is true that many disabled people have very limited education and training opportunities.

2.4.1 Schooling

At present there are three sectors in the Bolivian education system: *educación regular*, *educación alternativa*, and *educación especial*. Disabled people's education is largely within the third category. The state funds some staff salaries within this sector, but management and administration is largely done by NGOs.

The divisions within the current system are illustrated by the fact that, in November 2006, the Bolivian government instigated a high profile grant, known as *Juancito Pinto*, supposedly to all children under the age of 18 in schools. But initially it omitted children in *educación especial*. When the omission was pointed out, the first response was that this is a separate sector and not eligible. After some negotiation between government departments, those disabled children in schools did also receive the grant. However, as a representative of the Ministerio de Gobierno agreed "there are certainly many disabled children that do not go to any school".

The organisation Fe y Alegría, runs schools exclusively for disabled children, but is also trying to integrate disabled children in regular schools. They employ 15 people to help teachers in regular schools adapt their methodology to be more inclusive. Few state schools currently include disabled children. In Santa Cruz a social worker at Teresa de los Andes reported that only four schools accept any disabled children and these are all fee-paying, privately run schools.

Members of an association of disabled people in Montero complained that the cost of attending the 'special' school was prohibitive to most local disabled people. However, the school's director claimed that no child would be turned away and that parents pay what they can afford. Whether or not this is true, the fact that the school is perceived to be unaffordable must mean that many do not attend. It takes strong confidence to visit a school that is thought to be unaffordable and ask for price reduction.

The Ministry of Education began an awareness-raising campaign at the end of 2006. They used leaflets, posters and advertisements on radio and television, depicting a disabled child saying, "I want to be like you". This campaign and slogan was devised within the Ministry by the non-disabled staff. There does not seem to have been any consideration of whether it would have been more appropriate for the campaign to have been devised and led by disabled people. Nor whether the slogan is actually a positive message to promote, or an accurate description of the wishes of disabled people.

Part of the aim of the Ministry's campaign is to distribute information regarding the new educational reform bill, which proposes that all schools should be inclusive of disabled children. The *Congreso de la Educación Boliviana* took place in Sucre in July 2006. There was conflict both during the congress and after, and the Bill was not passed. Representatives from the *Confederación*

Sindical Única de Trabajadores Campesinos de Bolivia (CSUTCB) and the Ministry of Education spoke of the inequality between education provision in urban and rural areas, and between rich and poor areas. The educational reform bill aims to reduce these discrepancies and to make all schools inclusive.

According to the *Defensor del Pueblo* in Sucre, the situation is improving. Teachers are being trained to include disabled children in their classrooms. In 2005, there were 14 teachers trained in inclusion and 75 disabled children included in schools. In 2006 there were 22 teachers trained and more than 100 children included.

One school in Sucre does now have ramps, and one has a lift. But a representative from the department of education in Sucre reported that there is no pressing need to improve physical access to schools, “there aren’t many disabled people in these schools, that’s why they don’t need to be accessible. A few people are integrated, but not those that have very serious problems. They have to go to special education”. It would seem that his definition of “very serious problems” would be if the steps at the entrance to the classroom exclude someone. He went on to say that, “in rural areas, children have to walk long distances to get to the colleges”. As disabled children would not be able to walk large distances, there was again no need to consider access within the school. Another representative of the department talked of the need for more, “...specialised teachers. It isn’t easy to work with disabled people. They need specific centres for special education”. He then said the main problem was lack of resources and the need for “modern infrastructure in order to incorporate disabled people”. On more probing, it appeared that the modern infrastructure they thought was required was ramps!

Another school in Sucre specialises in including blind children. One class was observed for a short time in this school. The blind children sat together at the back of the class. The teacher said that, as she did not know Braille, she had no way of including these children. Indeed, she appeared to ignore them. Afterwards a focus group was conducted with these children. When asked what the children would like to change in their lives, one girl said, “I would like to see in order to help others”. When asked why she would need to see in order to do this, she said, “in order to read what is written on the blackboard”.

The department of *educación especial* in the Ministry of Education are trying to get specific training for teachers to work with disabled children, “up to now there is no training for special education”. Teachers are trained as ordinary teachers and then start working with disabled people. Similarly, the NGO *Aprecia* was planning a programme of teacher training at the time of the interview. Rapid staff turnover in *educación especial* was blamed on the fact teachers only get paid for 72 hours in this sector, whereas teachers in *educación regular* get paid for 96 hours.

The only place that provides any attention for deafblind children in Santa Cruz is *Aprecia*. Here, children receive one hour’s education, twice a week. The parents are well aware of the inequality in this, compared with what other

children get. Several talked of their wish to receive teacher training so that they can support their children's education themselves. One parent of a deafblind child spoke of her wish for her son to mix with other children: "they need to mix with other children, they are also children, they are not extra-terrestrials. These children are not different. It is the only way of getting tolerance in society". Special education may be better than nothing, but deafblind children need to learn skills just like anyone else. In this way, "they won't be a burden to society nor to their parents". The mural in Santa Cruz had a picture of a school for disabled and non-disabled children together (see 4.2.5 for full mural).

Integrated school in Santa Cruz mural



Parents of deafblind children asked *Aprecia* for teacher training. They said they would be more strongly committed than other teachers, "we don't want teachers that do it for the wage, but people who do it as a vocation". When this was suggested during the interview at *Aprecia*, the response was that the problem was that parents would want to be paid. It was pointed out that existing teachers are paid. It seems that not only is the idea of employing disabled people widely met with derision, but so is the idea of employing parents of disabled people.

Many deaf people complained at having to go to schools where teachers are not deaf and do not know Sign Language. Deaf people in focus groups in both Sucre and Santa Cruz spoke of the isolation they experience when among hearing people attempting to communicate orally. Several people talked of coming home from school in tears, because the teacher had not been able to understand them, nor had they understood the teacher. They spoke of the lack of understanding of deaf culture among hearing people and, in contrast, of the freedom experienced when among deaf people. The deaf people's mural in Sucre contains images of a community of only deaf people (see below and full mural in 4.2.2).

The school for deaf people in Santa Cruz has some hearing and some deaf teachers. Some of the hearing teachers are learning Sign Language, but there is a shortage of qualified deaf teachers. According to members of this focus group, the problem is that, in order to study in a hearing school, deaf people need interpreters and the government does not pay this cost. One member of the group reported that he had been forced to give up education, as he could not afford to pay for the interpreters.

A member of staff of a deaf school claimed that deaf children learn more slowly than hearing children. She denied that the communication barrier might be the cause of this. She did also mention the difficulty of finding deaf teachers. One deaf person in her contribution to the mural drew a picture of herself dreaming of teaching deaf children about their identity and their culture (see full mural 4.2.2). The reality is that until this vicious circle is broken, few deaf children will receive an adequate education and few deaf adults will become teachers.

Deaf woman dreams of becoming a teacher. Association of deaf people in the background - Sucre



The director of *educación especial* in the Ministry of Education in La Paz did not report any attempts to break this cycle by recruiting deaf people to train to be teachers. The lack of teachers specially trained for work with disabled people was seen as a problem, but not the lack of disabled or deaf teachers. It was claimed, "Sign Language is universal, we want to start with oral language." The director went on to assert that deaf people could learn orally as long as they start early enough.

In contrast to her perception, deaf people report different Sign languages just as there are different spoken languages. When people come together they develop a language, whether spoken or Sign. The limitation for deaf people is that they are often too isolated from each other to develop a language. In rural areas, several deaf people who took part in this research had not met other

deaf people and did not know any Sign Language other than the fragmentary one developed within their family. In these areas, deaf people had no schooling. The most urgent need they or their relatives spoke of was the need to learn Sign Language.

In Tupiza, the Director of Education admitted there were no disabled teachers that he knew of, nor any teachers focussing on working with disabled children: “education policies do not take account of disabled people”. He recognised that this was a problem, but spoke of the difficulty in getting the wider community to prioritise education, let alone education of disabled children. He talked of pressure on local authorities to spend resources on “material things. They say the priority is my bridge or the street”. He talked of his desire to develop a project to raise awareness among teachers of the needs of disabled people: “we need to change the mentality of teachers. They need to see these children deserve to be attended to”. At the moment, he says, “it seems that a disabled child is seen by teachers as an additional burden.” Awareness raising of teachers is needed first. But in order to make it politically possible to spend resources on such a project, it would have to be done in tandem with raising awareness among the wider population. The mayor of Tupiza spoke of similar concerns.

Sometimes the barriers come before the child gets to school. Several disabled adults reported that their parents had not wanted them to go to school, “my father was ashamed and for that reason he didn’t want me to go to school”. Another person reported that he started school at the age of 15 after his sister insisted on it. Before that, he helped his mother with housework.

In Tupiza, there was a meeting of approximately 40 parents and their disabled children. When asked what the priority was for their children, the parents overwhelmingly agreed that the most pressing need is for children to learn to defend themselves. They described how the children get teased and bullied:

- “They are hurt in the street or in the school”;
- “He is bullied at school, he doesn’t want to go back”;
- “Teachers don’t do anything”;
- “There is bullying from other pupils”;
- “Morality is gone”;
- “Children lack self esteem because of this bullying”.

Many parents spoke of how they had tried to send their children to school but that the children got bullied so badly that they had given up. Similar stories of bullying were reported in other areas and the blame was widely put on parents and adults. Children pick up their values from the adults around them. As one worker at an NGO in Santa Cruz put it, “they don’t teach respect for disabled children”.

The mural in Tupiza depicts the abuse disabled children experience when trying to take up their basic right to education (see full mural 4.2.4).

School with graffiti messages: 'we have the right to study'; 'I am your friend, do not discriminate against me' – Tupiza



Some parents said it would be better to have special schools so that their children would not face the abuse of non-disabled children and the indifference of non-disabled teachers towards them. As was said at the seminar to disseminate the *Plan Nacional de Igualdad y Equiparación de Oportunidades*: unless this discrimination is addressed, any laws regarding the right to education remain theoretical.

Despite all these problems for disabled children accessing education, a representative of the United Nations Development Programme spoke of the likelihood of achieving the basic Millennium Development Goal in Bolivia, “that all boys and girls complete a full course of primary schooling”. He went on to say that he is unaware of any work to include disabled people. But, he pointed out, as the poorest people are not registered in statistics, they will in any case not count in assessments of Millennium Development Goals.

2.4.2 Adult education and training

In many places, disabled people talked of there being far more opportunities available for disabled children than for adults. Whilst many disabled children may be excluded from schooling, there are at least some schools and NGOs that provide some form of support for disabled children. For adults, there is often no support whatsoever. Some parents of deafblind people complained that there is nowhere for them to learn Braille. *Aprécia* provides the only education for their children, but there is nothing for parents (see section 6.3.3 for further discussion of this issue).

In several places the only training disabled adults are offered is in handicrafts. Whilst this is what some people want to do, if it is all that is available then it is not surprising when disabled people lack the skills for wider employment. A leader of the national federation of blind people described it as an insult that an NGO only offers blind people training in bakery and sewing, and then

claims that because blind people have insufficient skills, sighted people need to run the institution.

Disabled people in rural areas frequently have even fewer educational opportunities than in urban areas. In Tupiza, an isolated small town, there is nowhere for blind people to learn Braille. This meant that when representatives went to the congress in Potosi, they were not eligible for election to the executive: “we were nominated to be executives but we could not do it, we do not know how to read Braille, because there is nowhere to learn...there is no school or anything.”

One disabled person spoke of having had to stop his studies in the final year. He was studying agriculture, but since he became disabled it is too difficult for him to get to the university, let alone enter the building. He cannot afford the fees now that he is no longer working, “now, after my accident, I have stayed here, I can’t carry on because of [lack of] funding more than anything”.

Members of an association of disabled people in Montero report, “With regard to education, in the association there are some people who cannot even read”. They called for basic literacy training and talked of their exclusion from existing programmes. The Bolivian government is working with the Cuban programme, “*Yo, si puedo*” / “Yes I can” to promote adult literacy. However, disabled people reported little access to this programme and many reported having had no formal schooling. The problem, according to them, was the lack of specialised teachers.

The two disabled people who staff the town’s disability unit agreed that few disabled people have been included in the literacy courses. But, according to them, the main barriers are that disabled people do not have the confidence to take part, they do not have physical or financial access to transport, or they are so isolated that they are not even aware of the existence of these courses. Some members of the association did call for literacy programmes staffed by disabled people. They said, “Between ourselves we understand each other. It would be good if we had a literacy centre and I am sure that many disabled people would come here because, as we say, we are the disability troop and we don’t have shame, we can move forward”. Whatever the reasons, all were agreed that there are currently high rates of illiteracy among disabled people and that few take part in existing literacy programmes.

For some disabled people the issue is not about learning literacy, but about having a use for literacy skills in their lives. If people have no access to books or newspapers and rarely even leave their homes, then learning to read may be low priority. One disabled woman in an institution reported that “I learnt to read a little before entering the home but afterwards I thought, ‘why learn to write if I am going to stay here for the rest of my life?’” 57 years later, she is living in the same institution and only goes into the outside world every few months. She has little use for literacy.

2.5 Basic needs

In Tupiza and surrounding communities people talked of their priorities being the basic material needs of any human being: food, water, shelter and clothing. According to members of the association of disabled people in Tupiza, “90% of disabled people do not even have enough to eat”. They described their priorities as “food and somewhere to live”. They talked of needing material assistance to encourage people to come to meetings. If people cannot afford food to eat or clothes to wear, then finding money to pay for transport to a meeting is low priority.

Similarly, a disabled person in a small rural community near Guaqui, said, “there are so many things I need, but primarily I would like authorities to help with basic needs”. People in a rural area referred to themselves as “human beings with feelings” who do not want to be treated as animals.

Blind people are the only disabled people that get an annual grant. But, in Tupiza, members of the Association described their precarious survival, depending as they do on this grant:

“Without economic means, if we do not have enough to eat, what can improve? Things will get worse. Now, suppose there were a small devaluation we would be ruined. If bread now costs 25 cents, it would go up to 50, instead of eating one piece of bread we would have to eat half. That’s how it is; visually impaired people here are without resources. How can we move forward?”

They referred to the five or six blind people in the old people’s home as having an easier life: “at least they are relaxed because in the old people’s home they are given everything, they eat well, they have all they need, breakfast, bed, clothes, they are given everything even shoes” (see section 6.3.4 for further discussion of institutions such as this).

2.6 Health care

A further priority for change that was often mentioned was the need for accessible health care, “health care in Bolivia is not accessible to disabled people”. Disabled people referred to barriers to health care relating to physical, financial and attitudinal issues.

Physical barriers

In rural areas it is particularly difficult for disabled people to reach a health centre. For example, a wheelchair user in a rural community near Guaqui described how, “I would have to hire a vehicle, only then could I travel. To do that I would need economic means, I would have to sacrifice my animals”. For deafblind people it is also difficult, “one goes to the doctor and has to wait all day, deafblind people find it hard to wait”

Financial barriers

Once there, the cost of consultation and treatment is often prohibitive:

- “Disabled people may get emergency treatment but if they have no insurance the situation is tragic. The majority of disabled people have no insurance”;
- “The majority of disabled people cannot receive medical care, they cannot pay for medicines”;
- “There is a lack of professionals who know about deafness, and they are very expensive”;
- “We need policies to help disabled people access healthcare. It is the most vulnerable sector”;
- “Doctors should show tolerance and patience, professional capabilities, and they should not be so profit-motivated”;
- The parent of a disabled child talked of needing treatment to control her fits, at least then the mother could leave her for a short time to go to work. But the cost of the medicine is unaffordable.

Financial access to health care is a huge problem for all poor people in Bolivia. As an NGO staff member working in the poor suburbs of Santa Cruz, put it, “the problem here is that people do not have money, they are not insured. They can’t get medical treatment”. There is free treatment for specific categories of people such as pregnant mothers and small children. NGOs can have small projects to help specific people, but the problem is large scale. Hospitals limit the amount of free or low cost care they provide. As this NGO worker put it, “Hospitals need to get their money as well.”

Attitudinal barriers

Even if the physical and financial barriers are overcome, there are additional attitudinal barriers from medical staff towards disabled people. Numerous examples of abusive attitudes of the medical staff were described:

- “Doctors say it would be better that he dies”;
- “Doctors have said to me, ‘why have you brought this girl that is going to die?’”;
- “They say to me, ‘why do you worry so much about a girl that has Down’s syndrome?’”;
- “They say non-disabled children are going to do something with their lives. They don’t give priority to children with mental impairments, for doctors it would be like wasted funds”;
- “We are tired of visiting doctors, now we just use home treatments and good nutrition to avoid illnesses. Doctors don’t accept us. They ask why we have brought him, better that he should die, the doctors reject him”;
- “Doctors look at him as if he were a rare insect. It’s better to find treatment at home”;
- “I always go to the doctor with another person. They push us in the queue. We have the right to be seen just like other people. I have had horrible things said to me in the queue”;
- “If my son has flu, doctors don’t even listen to his lungs or his heart”;

- “Doctors don’t want to waste their time with a deafblind person. Their attitude is very different to how they treat my other children”;
- “Doctors are for non-disabled people, not for others. The treatment is inappropriate. He has often got allergies from the treatment that doctors give”.

A training event on disability was observed in Potosi for doctors, nurses and social workers. A total of 56 fully qualified professionals attended this training, which was the first any of them had had on disability. The training was delivered by a non-disabled person from the NGO, *Rehabilitación Integrada en la Comunidad* (RIC). Participants were asked how they feel when they see a disabled person. They responded with: “sorrow, pain, sadness, impotence, anger at not being able to do anything”. There seemed to be little or no understanding that disabled patients have the same rights to treatment as non-disabled patients.

According to staff at Plan International, many people in rural areas do not go to health centres because they do not trust the doctors. They prefer to use the healer in their community rather than travel to an expensive doctor who will give expensive medicines, whose efficacy many people are unconvinced of. The NGO staff did not say this, but it may be that resources would be more appreciated if spent supporting traditional healing.

Communication barriers

If all the other barriers are overcome, for deaf or deafblind people there is still the issue of communication. Interpreters are not provided at health centres - deaf people have to provide their own. As one deaf person put it, “I have had problems with doctors. It is difficult to find interpreters, we don’t have money to pay them”. Or as a deafblind person said, “Sometimes doctors don’t understand. They don’t speak loud. A doctor is to attend to patients. We are not all the same. They need to have patience and speak loudly”.

It is probably because of all these barriers that staff at the health centre in Guaqui, who are responsible for 8789 people, reported that “we don’t have any disabled patients”. The doctor at the health centre claimed the absence of disabled people is because they go straight to La Paz for rehabilitation. It seems that some medical staff perceive disabled people as having no health care needs other than rehabilitation.

In Tupiza, forms are filled in for everyone that attends health centres in order to assess their level of risk and to decide whether and how much assistance they qualify for. The only place where impairments would be considered would be under the section for illness. The level of help people get depends on their housing, income and health. Some assistance with the costs of health care may be provided, but no help is provided for rehabilitation after an accident, for example. The network of health professionals used the information from these forms to offer names of disabled people in their area. The lists were provided at the end of the research period in the area, and, interestingly, did not include a single name of the disabled people who had taken part in the work. This may be because the majority of disabled people

do not go to health centres for the reasons outlined above. Many would in any case not often require it, being disabled but not necessarily unhealthy.

2.7 Transport

Disabled people in all areas talked of difficulties in using public transport as one of the biggest problems. A similar range of access issues relate to transport as to health care. The majority of buses are very difficult for wheelchair users to access. Sometimes it is physically possible if people are manually lifted, but contrary to the law, people are often charged extra for the chair. There are also numerous examples of abusive attitudes of drivers and passengers towards disabled passengers. Transport issues appear in several of the murals. In Tupiza, and Tiahuanacu wheelchair users drew images of buses driving straight past them without stopping (also full murals 4.2.4 and 4.2.6).

Bus leaves wheelchair user behind - Tupiza



Bus leaves wheelchair user behind – Tiahuanacu



In some areas transport is free or reduced cost for disabled people. In Sucre bus transport is now free for disabled people. This policy met with mixed reaction. One disabled woman said she now preferred to walk, however long or difficult it may be. She said she wanted equal access to employment so that she can pay for her fares, not to be patronised with free fares. Other people on the bus were sometimes abusive when they realized she would not have to pay.

Blind people and deafblind people theoretically receive free transport, but several people reported how difficult it is to get buses to stop for them. Other passengers are frequently hostile to stopping for the extra time required for a blind person to get on. As they do not pay, the driver has little incentive to stop. For this reason it was said that, "drivers prefer to take other people".

Although the law says that disabled people should not have to pay extra for travelling with mobility aids, this rule is rarely observed, "the majority do not respect this". Company bosses do not comply. Sometimes it is physically impossible to fit larger mobility aids such as tricycles onto the bus. On occasions when drivers do take wheelchair users, they often charge more for the extra space. This means that, as Jaime Estivariz, the President of Cobopdi put it:

"Life is much more expensive for disabled people. I wish we had even a small discount on journeys, but it's actually the reverse. We pay more for transport because we sometimes have to go by taxi, sometimes even a taxi won't take us. Why? Because there isn't an appropriate vehicle to take us."

Another wheelchair user described the difficulties of using buses. He then said that, if he is to travel, his only alternative is to rent a vehicle himself, but for this he would have to kill a cow or a few sheep. He has done this when it was essential to get to the city but the family depends on the meat and milk from their few livestock for survival.

Other passengers often abuse those disabled people who do get on buses. There are complaints that a wheelchair user might take a little longer to get on and might need some help. Passengers make comments such as, "we are getting late, hurry up hurry up...why are you taking this person?".

Parents of deafblind people in Santa Cruz described how they are regularly insulted on buses. Deafblind people can be very tactile, as they explore their surroundings. Other passengers frequently react with hostility even to the touch of a two year old, making comments such as "why do you bring this child out, he should stay in the house". One parent described how people act as if her deafblind son had an illness, "they don't want him to touch them, they don't want us to sit next to them".

For some disabled people, such as a wheelchair user in a rural area, the solution is to avoid travel where possible. He said:

“I can’t even go to my village which is five kilometers away, let alone go to the town, because transport workers don’t want to take us. It seems that for them we just take up space, we take up their time. In minibuses they don’t even let us get on carefully. The first time they took me, I injured my foot even worse because of rushing. That’s why I prefer to stay here; I don’t go to the city anymore, I just stay here. Also I need money to travel so it’s better to stay here”.

Several people spoke of the need to lobby and inform transport companies, unions and workers. One person accused the association of transport workers of ignoring the needs of disabled people, “they don’t think of the needs of disabled people”. Many people thought part of the problem is that drivers are not aware of their legal obligation or the needs of disabled people. This could be improved with information. Other people thought there was no hope trying to make regular transport accessible, the solution would be to have “special buses to transport disabled people”.

2.8 Attitudes and perceptions of disability

Many disabled people in focus groups mentioned their frustration at others’ lack of belief in their abilities. Sometimes this lack of belief is from friends and family, sometimes from wider society:

- “Society takes us as useless people, but we can do things”;
- “My friend said to me, you won’t be able to do that...sometimes because they see you in a wheelchair, they think you can’t do anything, that we aren’t good for anything. But it isn’t like that”;
- “Up to now people see us as beggars”;
- “We did some serious work... I went to present it to someone in an institution...they said, ‘you did that?’ They didn’t believe that it was my work. That’s to say they don’t value the work of a disabled person”;
- “I said to my friend, ‘let me do that’. The other day I met up with my friends and again I had to remind them that I can do that mental or physical task. I constantly have to remind my friends that I really can”;
- “Other people think this disabled person is no use. There is no faith in disabled people”;
- “Even in the family sometimes they say: ‘you haven’t done that’”.

Some people talked about family attitudes towards disabled relatives as a major difficulty. Some disabled people described positive support from their families, but many described other family members as being over-protective, showing shame or lack of belief in their abilities, or denying the reality of life as a disabled person. A wheelchair user in a small town asked her teenage son if he would help her draw a picture for the mural design, saying he was better at drawing than her. She asked him to draw herself in her wheelchair being hit by a neighbour. He drew a happy scene of market day in the central square. When asked which person was his mother, he pointed to a woman standing chatting in a group. He then suggested that we take a photo of her

seated in an ordinary chair at home. She talked of how difficult it was getting to the city now that her husband had died. She said, her son, “is ashamed or scared” to be seen with her in the city. Indeed when the two of them did come to the opening of the exhibition of murals in La Paz, he initially left her outside in the rain while he came into the gallery to represent her.

Some disabled people seem to take the shame or low expectations from others as a challenge and are determined to prove their abilities. A deafblind woman described her determination: “Our parents don’t accept our disability, but we are as we are. We want to show that we can do things”. A wheelchair user reports telling a disbelieving friend, “I said to him I will be able to, and I will be able to”.

Others seem to accept these expectations as the reality. Participants of two separate focus groups of disabled teenagers living in an institution were asked what they would like to change in their lives. The responses were largely about changing aspects of their own personalities:

- “I would like to change my manner of being”;
- “I have developed badly, I moan a lot”;
- “I want to change my attitude”;
- “I want to be more independent”;
- “I want to be more optimistic”;
- “I want to be less capricious”.

There was little notion of any possibility of changing anything except their personalities, although one member of the group did talk of the wish “to be accepted as we are”.

The perception of what can be done as a disabled person was very varied. One disabled woman talked of her sadness that she is not able to dance because she is disabled. Another person responded by saying he really enjoys dancing, he just dances on his knees. Blind people in a group in Tupiza had very low perceptions of their own abilities. They reported:

- “We can’t do anything”;
- “We can’t work”;
- “We aren’t trained”;
- “We can hardly do anything”;
- “We don’t have vision, so we can’t do anything like other people can”.

The level of acceptance of disability varied among disabled people themselves. The Director of one branch of Codepedis was criticised by other disabled people for not responding to the need for wheelchairs. He responded by saying that if people can walk even a little they should not be given a chair, “It’s not pretty to use a wheelchair”. The same person showed a similar perspective when he made a presentation showing a photo of a ‘perfect’ non-disabled baby followed by a photo of a person in a wheelchair. He said that prevention was important to prevent the baby ending up in a wheelchair. His point was dramatically lessened by choosing a photo of a very happy looking wheelchair user!

Other disabled people talked of the lack of support from society and how disabled people are treated as if they have no emotions. As one person put it, “people think that one is made of metal”. In contrast, another person was strong in her condemnation of those who dwell on self-pity, “I don’t like self-pity...it’s the worst defect I see in people. I see myself as a normal person, I don’t like self-pity.” Others say that their self-pity is only a reaction to the way they have been treated.

Attitudes towards disability among people who have been disabled all their lives or for a long time and those who have become disabled within the last few years were often markedly different. Several people who had become disabled in the last few years were very depressed by their situation. These people found it hard to consider the notion of a life as a disabled person and focussed on wanting back their old lives. One girl, who had recently become brain damaged in an accident said, “I want to get well”.

Among people who had been disabled for a long time this perception was rare. Even among the young people who wanted to change aspects of themselves, there was little mention of wanting to change their impairment. One person said, as on the title page of this report, “I don’t have any problem, the problem is theirs”.

Many non-disabled people who were interviewed seem to find this notion difficult to comprehend, as is clear by the awareness-raising campaign by the Ministry of Education (see section 2.4.1) or the focus on rehabilitation (see section 3.1). There was a wide-spread unquestioning assumption among non-disabled people that disabled people have a problem, as illustrated by the following quotes that were repeated many times by non-disabled participants:

- “Those that have a problem”;
- “People with problems”;
- “Where we have more people with problems”;
- “People who have the problem of disability”;
- “Problems of disability”.

When trying to gain access to the office of Codepedis in Santa Cruz, the security guards were unaware of what the office was until eventually one of them referred to it as the office of ‘deformed people’.

2.9 Architectural barriers

A report on the difficulties faced by disabled people in Bolivia would be incomplete without some discussion of architectural barriers, although this issue did not come up frequently in focus groups. One disabled person did talk of the architectural barriers:

“I wish they would put something on the pavements where wheelchair users can go up. That’s a problem too. When I was in La Paz, I nearly fell out because of the pavements. I see on TV that in other countries there are places for going up and down pavements. There are even

institutions with lifts, but here in La Paz I came across this problem when I went to the city. Buses too: when I was in Argentina, I saw buses with specific seats for wheelchair users, but in this city we are totally forgotten...”

Many of the examples of architectural barriers come from the researcher’s observations rather than from what was said in focus groups. There appears to be a high level of acceptance of such barriers among disabled people. The inauguration of the new committee of Codepedis took place in an inaccessible room. Wheelchair users were carried down the steps.

Entering the inauguration of the new Codepedis directorate.



The Conalpedis office in La Paz has a flight of stairs up to the main door. It appears to be accepted that wheelchair users get carried up steps. In Potosi the staff of Codepedis chose to move from an accessible office that was dark and cold to an office to one that has more light, but is not wheelchair accessible. The only disabled member of staff there is able to get up stairs. When disabled people in this area were given cameras to take photos of the barriers in their lives, many took photos of the entrance to this office.

A camera was also given to an association of disabled people in Santa Cruz to record the barriers in their lives. One blind man got photos taken of him encountering pillars and holes in pavements and of the difficulties in crossing roads. His image was represented in the mural in Santa Cruz (see 4.2.5).

Santa Cruz blind man finds obstacle in street – mural replicates photo.



The seminar to promote the *Plan Nacional de Igualdad* was at the Ministry of the Vice President – on the first floor, up a long flight of steps. At the end of the seminar, disabled people thanked the Vice President for having allowed use of the room and said they hoped to use the same room again.

A Cuban woman at this meeting remarked on how few disabled people, apart from beggars, she sees on the streets in Bolivia. She said that she had noticed how inaccessible the streets and most of the buildings are. Similarly, a civil servant remarked that the invisibility of disabled people is partly due to architectural barriers: “architectural barriers mean that disabled people can’t walk here, that makes them invisible”.

3. Priorities emerging from interviews with non-disabled people

The following section relates mainly to the priorities mentioned by non-disabled people in interviews, rather than by disabled people. Some non-disabled people recognised the priorities of disabled people as being issues of discrimination, particularly in the areas of work, education, healthcare and transport. But many were focussed on more medical issues, directed at changing the individual rather than any fundamental changes to society.

3.1 Rehabilitation

Issues of rehabilitation often came up among the priorities perceived by non-disabled people. In focus groups of disabled people, it was noted that when people considered the main difficulties in their lives, followed by how to solve problems, rehabilitation rarely came up as an issue. If people arrived late, at the point of discussing priorities, without having discussed the causes of the problems, there was more frequent mention of rehabilitation.

Many NGOs focus on rehabilitation, whether of a traditional medical nature or Community Based Rehabilitation. As has been discussed, these organisations are very rarely led by disabled people and rarely even employ disabled people. One worker from an NGO that has a policy of prioritising disability was clear that the main need is for expert occupational therapists. This was not a need mentioned by disabled people.

This is not to deny that some disabled people talk of the need for rehabilitation (most commonly those who have become disabled through accident or illness, where rehabilitation was useful to them personally). In Patacamaya a group of disabled people are organising a centre for rehabilitation. The leader of this group is a disabled man who was injured in an accident as an adult. He has very positive experiences of rehabilitation services, "It is thanks to a rehabilitation centre that I am living. I've seen many disabled people who have not had access to rehabilitation services, that's why I have this vision."

For him, it was through rehabilitation services that he found out about the Disability Movement and became active in setting up a disabled people's organisation. He describes how, six years after his accident, he was neither aware of the law, nor of his rights. His rehabilitation was only accessible to him because a volunteer paid for it. In the hospital, a doctor casually mentioned to him that there are organisations of disabled people. He went to find the federation in La Paz. It was then that he learnt about his rights and decided to set up an organisation.

Rehabilitation is useful for some people, but there is no inevitable association with disability, as some non-disabled participants implied. On those occasions when disabled people mentioned the need to change something about their impairment, on further probing the issue was often the desire to change the

response of society towards that impairment. Some disabled people objected to the focus of some NGOs on rehabilitation, whether based in the community or in an institution. One particularly vocal person on this issue talked of how the implication of rehabilitation is that the individual needs to change. This lowers self-esteem and deflects from the fact that what needs to change is the systemic discrimination that currently exists.

The assumption among many non-disabled people that the priority, indeed the only hope, is rehabilitation, was seen in many contexts. The *Centro de Paralisis Cerebral* (CPC) is a centre for children. Their logo shows a person in a wheelchair reaching out saying 'help', followed by the same person getting out of the chair saying 'hope'. This notion that hope could only come from getting out of a wheelchair was not shared by many disabled participants, other than some people who had recently become disabled.

Banner of *Centro de Paralisis Cerebral* (CPC)



At the health centre in Guaqui, it was said that the reason they only knew of one disabled person in the area was because others “go straight to La Paz for rehabilitation”. Staff nearby at Plan International expressed a similar view “if they can, they go to La Paz”. They say that people sell animals, and borrow from neighbours in order to pay for rehabilitation.

Staff at Plan and at the health centre were both actually referring to the same disabled person who had become disabled in an accident. This person described how, after his traffic accident, a doctor had asked for \$1500 to treat him. He could not pay, his drip and painkillers were stopped, and his leg became septic. He had to raise \$700 from relatives and friends in order to get the leg amputated, or he would have died: “we had to sell all the little we had. We had to borrow from one side or another, we had to kill our animals, that’s how we tried to get my left leg cured. Finally they did the surgery.” As he put it, “it’s the economic part which is most difficult for us, it’s impossible for us”.

For a great many people, basic medical services including rehabilitation services are prohibitively expensive. In Tupiza, people who need more than the local health centre provides, have to travel several hours to hospital in Potosi, paying transport and hospital costs.

The *Defensor del Pueblo* in Tiahuanacu reports that when they find disabled children, they try to send them to rehabilitation centres in La Paz. There is an unquestioning assumption that this is what disabled children need. When asked what happens to the disabled child after that, the *Defensor* said, “from there we don’t know, we can’t do any follow-up”. According to him, the greatest priority for disabled people is for a local rehabilitation centre.

A trainer from the Cochabamba-based organisation *Rehabilitación Integrada en la Comunidad* (RIC) referred to the problem that there are only 711 professionals specifically trained to work with the approximately 900,000 disabled people that exist. There is an assumption that disabled people need professional specialists. There is no mention of whether these ‘professionals’ are disabled people, or have any personal experience of disability themselves.

There seems to be a widespread assumption that rehabilitation could ‘cure’ disability if there were access to the right treatment. Whilst this research was being carried out, Cuban doctors in the programme, *Operación Milagro* were providing treatment for people with eye disease. An article in the newspaper *El Juguete Rabioso* (July 23rd 2006, p.12) quoted a Cuban doctor saying, “We want to eliminate blindness from Bolivia. People need to know that every patient that has lost their vision can get it back with our free treatment. We are working for zero blindness”. Whilst providing such medical treatment is appreciated by many that receive it, the goal of zero blindness has not been achieved in any country. It gives dangerously false expectations, perhaps making it harder for those that are blind to accept their impairment, certainly doing nothing to address the attitudinal barriers faced by blind people.

3.2 Prevention

Prevention was rarely mentioned in focus groups of disabled people but often mentioned by non-disabled people in interviews. The implication of a focus on prevention is not to prevent the injustice and inequality associated with disability, but to prevent a medical condition. In the training of medical staff run by RIC it was said that “the best treatment is not medicine, it’s called prevention” and that “rehabilitation is very expensive, prevention is more economical”. There seems to be an underlying assumption in this focus that prevention of impairments is both possible and desirable. Similarly the disabled person who introduced the non-disabled RIC trainer, spoke of the positive move towards work on prevention so that it would be possible to “reduce the number of disabled people”.

A civil servant spoke of disability being caused by malnutrition among poor women when pregnant:

“I have work and I will ensure that she eats well. But someone who has no work who can hardly look after his four children and his wife, then his wife is pregnant...for sure there is a high chance that the baby will be disabled. One mother had four children, none of them were disabled but the fifth is, why should that be? Did she not eat enough salt, or not enough vitamins?”

It was often assumed that there is less disability among rich people in richer countries, when in fact the reverse is true. According to World Bank estimates, there are more disabled people in richer countries, where better living conditions mean people live longer, surviving accident and injury more often ⁶.

There is a somewhat destructive message behind a focus on prevention. At the entrance to the school for deaf children in Sucre there was a poster stating: “Prevention of deficiencies, disabilities and handicaps is everyone’s task. Sumi [state health benefit] has funds for preventing them’. This poster was sponsored by several agencies (USAID, RIC, Prosalud and Socios para el Desarrollo) with no apparent involvement of any organisation of disabled people. Deaf children pass this poster daily, with the intrinsic message that as they are already deaf, they have somehow failed.

If the aim is to prevent, then there is some level of blame of those who fail. Those who were blamed in the course of this research were overwhelmingly those already struggling: families and particularly mothers of disabled children. The RIC (Rehabilitacion Integrada en la Comunidad) course mentioned the need to teach women how to prevent getting a disabled child; parents, how to prevent accidents at home. No mention was made of the need to prevent companies from cutting back on safety equipment and insurance costs.

3.3 Attitudes of families

Many non-disabled people focussed on the need to change family attitudes as a priority. Numerous stories were told of families hiding their disabled relatives away. As one non-disabled respondent put it, “disabled people are hidden away, therefore what is needed is to raise awareness among families”.

In Sucre, a civil servant justified the lack of employment of disabled people by saying this is not the priority; families need to be influenced first. A small NGO in Tupiza talked of the priority as being to stop families hiding their disabled relatives. The trainer of a group of doctors, nurses and social workers quoted the WHO figures of 10% disabled people in any society. She then explained

⁶ Estimates cited by the World Bank are that there are 4% for developing countries and 7% in industrialised countries.

that the reason so few disabled people are visible in the streets is because families hide disabled relatives away.

When this is put into the context of the existing systemic discrimination, the family can be said to respond to an inhumane situation in a rational manner. It is only by changing the discrimination that there can be progress. Blaming the family deflects attention from the wider causes of the problem.

4. The Murals

4.1 The mural process

Murals were used in each area of research. They often became the public face of the research, causing passers by to stop and talk, as well as attracting a lot of media attention.

Murals of any kind are much less common in Bolivia than in other parts of Latin America, such as Mexico or Nicaragua. There is graffiti, but rarely of the skilled, creative, aesthetically pleasing kind, commonly referred to as street art. Instead there are crudely painted or stencilled murals promoting political ideas or parties, which are quickly painted over by opposing groups. Sign writing by hand is very common and is extensively used for advertising. Painted murals of company logos replace the poster campaigns that are ubiquitous in the UK.

In Tupiza, a painter is employed to paint nothing but Coca Cola advertising on walls. He admired the disabled people's mural, but claimed he would be unable to produce anything like it. He is clearly able to draw confidently on a large scale (albeit within a very narrow range of subjects) but he has no experience of community art. It is probable that his attitude is a manifestation of the way that art has been distanced from the majority in Bolivia as in most of the world.

The 'art' murals that do exist all seem to be by professional artists or their students. There is little evidence of murals produced by and for community groups and expressing their own ideas. Many participants in the research did not know what a mural was until it was explained to them. Once they understood, the idea of sending out a message about themselves, their priorities and the obstacles facing them, appealed immediately. They were eager to express the many negative aspects of their lives, as well as their positive hopes but, almost without exception, they felt initially that they did not have the skills or aptitude to be involved in the actual production of the work. Most had no experience of drawing or painting. They wanted the mural to be provided for them by the artist. Once it was explained that it was their ideas that mattered not their drawing style, inhibitions were overcome. In contrast to this in the UK, groups are usually interested in working on a community mural, but wary of putting their own messages in.

There was greater reluctance to be involved in the painting process in public, which seemed to be seen as a step further away from people's experiences. However, once they did become involved, participants quickly assumed ownership of, and pride in, the mural.

Visual representation of disability

Internationally and throughout history, visual representations of disabled people have been rare, positive representations even more so. When disabled people have been represented, it has usually been negatively, or in such a way as to hide their impairments. The FDR Memorial in the USA (unveiled in 1997) hides the ex-president's wheelchair under a large cape

This desire to hide an impairment manifested itself during the research in the desire of the son of a disabled woman to have his mother photographed seated in a chair at home instead of in her wheelchair. His mother, claiming to be no good at drawing herself, asked her son to draw the aggression she faces from her neighbours. Instead he drew an innocuous picture of the town square, featuring her standing up, which she is unable to do (see section 2.8).

The design and painting processes began immediately after the oral discussions of a focus group. With their minds still fresh on the subject, people were given paper and pencils, or in some cases clay was used for people to draw or put shape to their ideas. They continued to talk as they worked, so further ideas were formulated or refined at this stage. When they had finished, they explained their drawings or clay figures, stimulating further discussion and immediately refining ideas.

In Santa Cruz one person suggested that NGOs are so distant from disabled people that they should be depicted on top of a tower drinking fine wine with money, supposedly for disabled people, in bags around them. Another participant, on hearing this idea, intervened saying some NGO staff try to reach out to disabled people. Others agreed but said the trouble is that NGO staff are physically and culturally so distant that they cannot reach even if they try. In this way the final mural design was developed. One person is trying to reach down from the tower to the disabled people organising on the ground below, but the distance is too great (see mural 4.2.3)

During the discussion with a group of young people with learning difficulties, it was unclear whether they had understood the point of the work, let alone how drawings could use metaphor rather than by merely representational. Then one participant drew a picture of a girl standing alone outside a house. She explained that several people live happily in the big house. The girl would like to live with them, but she has problems. They don't have problems so they do not want to live with her. In the final mural her drawing is on the left next to the wheelchair user (see Sucre mural in section 4.2.1).

This example exemplifies one of the unique strengths of this approach to research. If this girl had not been involved in the drawing stage, these ideas would not have been expressed, let alone portrayed in a prominent place for passers by to see and ponder. As it was, her message was unequivocal. The commissioners of this research assumed that it would not be possible to work with people with learning difficulties themselves, only with their parents.

Indeed this belief was so strong that the evidence was ignored and their edited report states that this was the case.

After the discussions, the drawings were taken away and a design was produced bringing together all their messages, sometimes copying the original drawings faithfully, other times just taking the idea. When the draft was finished, the drawings were returned to their owners and refinements to the design were discussed (see for example section 4.2.1 for the inputs that made up the Sucre mural).

After each mural was completed, a public inauguration event was held. This brought together disabled participants and non-disabled representatives of local authorities and the media in a way that would not have happened otherwise. The participants got to speak to a wider public (and, importantly, to people in power) about the issues that concern them. Invited dignitaries were obliged to think about local and wider disability issues in order to prepare their speeches. The opening event of the exhibition in La Paz repeated this. It also brought disabled people together from around the country, allowing networking and strengthening of solidarity (see 4.2.7 for a description of this event).

The community murals serve many functions. Many passers-by commented on the beauty of the art in itself. This caused them to stop to see what was happening and to interact with the painters or to examine the messages when the painters were not there. Almost without exception their comments were appreciative and supportive.

Passers by examine mural - Tupiza



Seeing disabled people working, contributing to an aesthetic improvement to a public place, contradicts the stereotypes many non-disabled people have of disabled people. A mural can help change public attitudes towards disabled people in this way as well as through the visual messages it contains. It can also change the participants' own attitudes: reinforcing confidence and laying claim to a public space for themselves through their painting.

This combination of murals with more traditional research methods proved to have numerous benefits as outlined in the box below:

ADVANTAGES OF RESEARCH/MURAL COMBINATION

- Murals have immediate impact on audience and participants. They are easier to relate to than an academic report alone.
- Ideas come out of the drawing and mural design that do not come out in verbal discussion.
- A group works together on a project encompassing many people's ideas. This helps build understanding within the group.
- Determining the mural design encourages participants to think more deeply about their priorities and the causes of difficulties.
- Creating the mural helps to change attitudes:
 - passers-by see the work being done, and stop to talk and see what is happening.
 - disabled people are seen to have contributed something beautiful and so get more respect.
 - participants physically and metaphorically claim a space in the community through the public art.
 - participants get a sense of pride and ownership of the final product.
- The finished mural is beautiful in itself, causing passers by to stop and consider the messages conveyed.
- The opening ceremony means participants encounter authorities and vice versa, in a way that would not usually happen.
- The easily accessible nature of the finished product leads to far more media coverage than an academic report would get alone, disseminating the messages of the research more widely. Television companies were particularly interested in covering the process of creating the mural as well as the final product.
- A mural functions as an advertisement, with the contact details of the local disabled peoples organisation.

4.2 Descriptions and photographs of the murals

4.2.1 Sucre – mural by disabled adults

A wheelchair user described sitting in darkness and isolation at the beginning of a road that leads to daylight and inclusion. The road is long, stony and dry with many obstacles. However, he is determined to get there and also to help others on their journey. His drawing was crude, but his idea formed a major part of the mural design. This figure in the mural is recognisably the participant himself.

A girl stands next to this wheelchair user in the mural. The person who drew this said the girl is alone but wants to live in the big house with the 20 families who live happily together there. The girl has problems; none of the people in the house have problems, so they do not want to live with her.

Another person drew a house to represent Bolivia and said disabled people, women, indigenous people and poor people are working together to build a new country to house everyone fairly.

Another person described how the problem is not for lack of resources. This person's drawing was of an NGO worker with arms outstretched to catch dollars falling from the sky supposedly for poor and disabled people. The money is then used by an elite, including NGO staff, to build luxury lifestyles apart from the rest of the country. Where most people live, the rivers run dry and the soil is barren, while where the elite live is lush and verdant.

Another person drew a bird, saying he would like to be free to move around like a bird overlooking what is going on.

These ideas were combined and adapted to make the final mural as shown below. People from different backgrounds, some indigenous, some disabled, are on the journey to enter the new Bolivia, represented by a house. There are dollars raining onto Bolivia. But a tiny minority escape in a van, using this money to construct luxury lifestyles, while poor and disabled people fend for themselves.



Este mural fue pintado por
los jóvenes con discapacidad
de la zona.
¡Juntos construimos una
mejor sociedad!

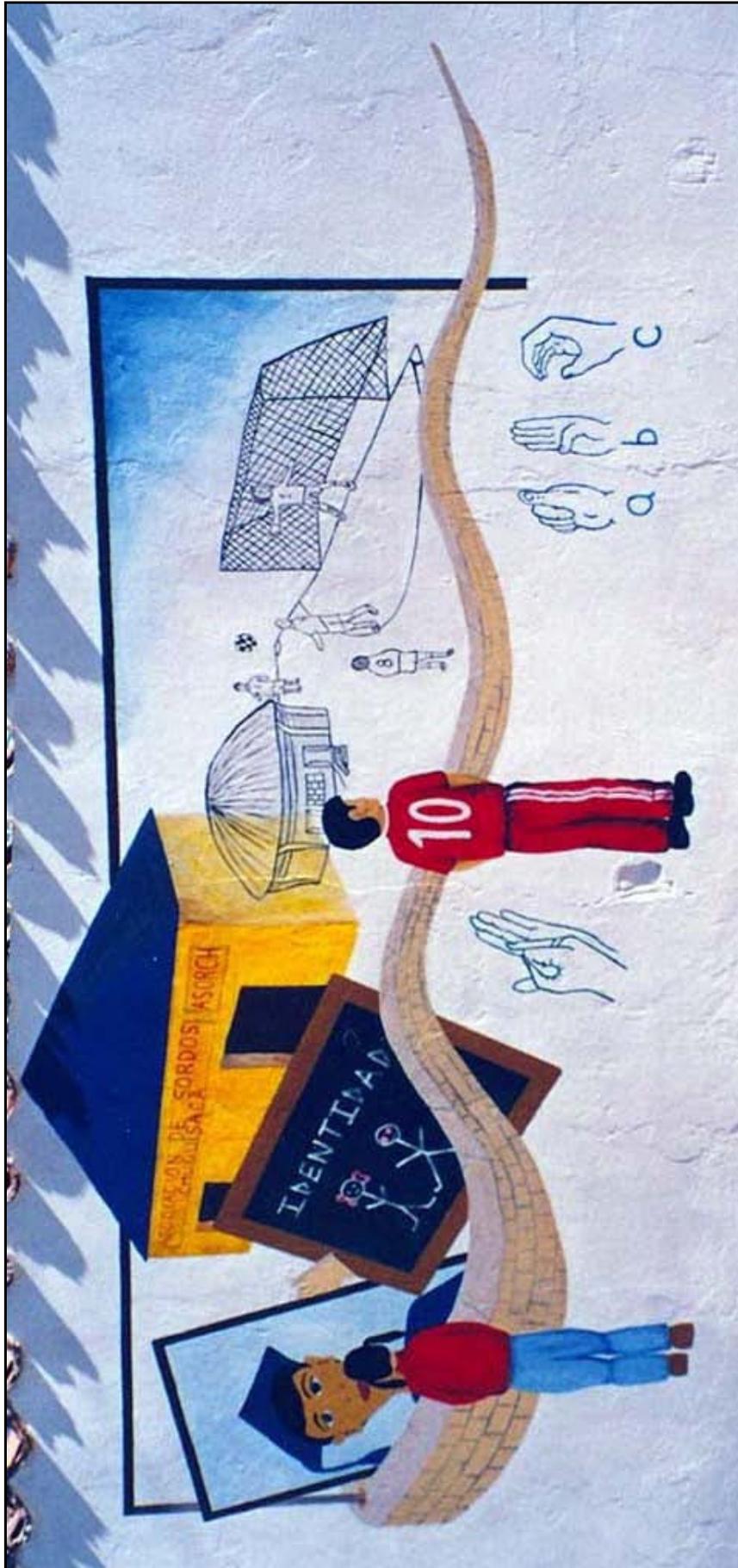
4.2.2 Sucre - mural by deaf people

A wall divides deaf people from the justice they are working for.

A girl looks into a mirror and sees herself as a teacher. The current education system rarely provides teaching in Sign Language, excluding most deaf people from the opportunity to gain the qualifications needed to become teachers themselves. The person looking into the mirror would teach deaf people about their identity if she could become a teacher.

Several people spoke of the need to have a centre just for deaf people. They spoke of the freedom they feel when surrounded by deaf people using Sign and the isolation they feel amongst hearing people.

A boy, dressed ready to play, watches a football game from the other side of the wall. He would like to play professional football, but as they use a whistle he is excluded. If only they would use visual signs he would be able to play.



4.2.3 Sucre - mural by disabled young people

This mural was made by young people living in different institutions, with visual, mental or physical impairments.

As part of the research process, disabled people in focus groups were asked what, if anything, they would like to change in their lives. One blind girl who contributed to this mural, was among the very few who mentioned something about her body. She said she would like to be able to see in order to help people. When asked why she would need to see to do this, she said she had to know what the teacher, in her supposedly inclusive school, was writing on the blackboard, so that she could explain it to the other blind pupils.

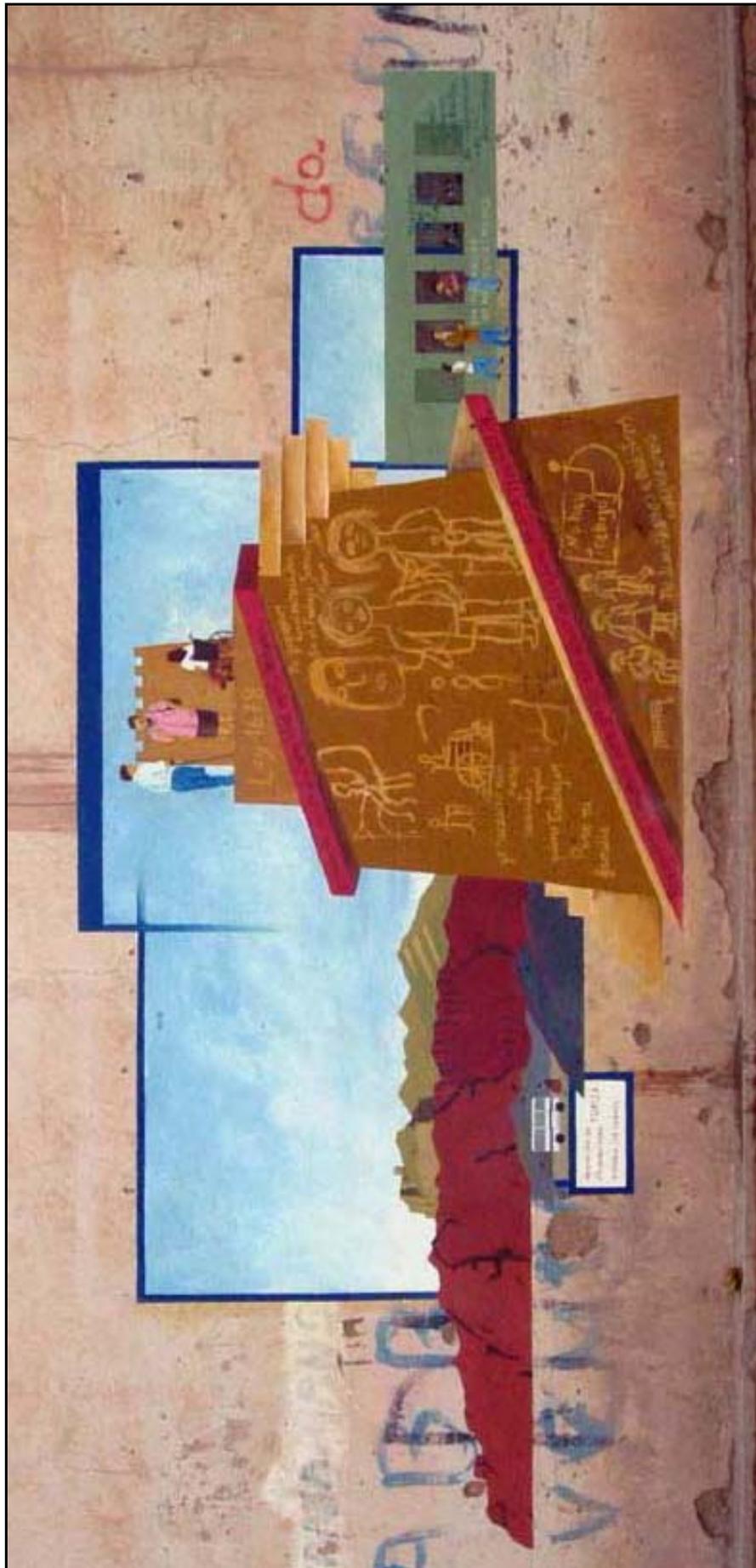


4.2.4 Mural in Tupiza, Potosi

In the centre of this mural is a tower, made accessible with ramps. Disabled people have climbed to the top and are calling on others to join them in campaigning for a more just society. The walls of the tower are covered with their messages.

On the left, a wheelchair user waits in vain for a bus. On the rare occasions that a bus stops for him, it is difficult to get on board, and he is frequently charged extra for his wheelchair.

On the right of the mural, there is a school where disabled people are claiming their right to education. About 40 parents and disabled children were asked what they would like to change. The parents, almost unanimously, said that their children needed to learn to defend themselves. They spoke of numerous occasions where children were bullied or insulted in the street and at school. Many had removed their children from school because of the abuse received.



4.2.5 Mural in Santa Cruz - by disabled people and parents of disabled people

On the right there is a tower with neither steps nor ramps. On top of this tower are people from NGOs and authorities. They are drinking fine wine, with bags of money beside them intended for disabled people and poor people. A lonely figure reaches out from the tower, but he is too distant and isolated to reach the people on the ground below.

At the base of the tower, a blind man bumps into a pillar in his path. A disabled woman searches in the rubbish to find some way of surviving.

Meanwhile, on the other side of the picture, disabled people are organising for a better world. They are cultivating the ground, building an inclusive school and campaigning to get work, justice, equal rights and recognition of sign language.

In the sky above, there is a flock of geese. A member of an association of parents of disabled people described how, to him, the association provides support in a similar way to the solidarity of geese. If one goose has a problem it comes down to earth with two others. They support each other until all are fit to fly again.

The sun represents the idea that no person should feel superior to another. The same sun rises and sets for everyone.



4.2.6 Mural in Tiahuanacu, Province of Ingavi

This mural, close to the famous pre-Inca ruins at Tiahuanacu, contains the ideas of disabled people from nearby towns and communities. In this more rural area, where disabled people are not yet organising, it was much harder to find disabled people. People were invited to participate through radio announcements, community meetings and by talking to the few disabled people visible on the street. This led to involvement of a few individuals rather than of groups.

One wheelchair user living in a rural community spoke of the difficulty of manoeuvring a wheelchair along dirt tracks. If he does get as far as the road, few buses will stop for him. He spoke of his isolation from other disabled people and of how useless he feels in a community that depends on physical labour to survive.

A woman living in a slightly bigger community spoke of the rejection she experiences from her neighbours. She rarely gets any help from them. She is able to travel if she has an assistant, but since her husband (who was also disabled) died, this is more difficult.

A 7-year-old child spends all day in a cot, at home with his visually impaired aunt, while his father is out working. He is unable to walk or crawl, but it is unclear how much practice he has had outside his cot.

4.2.7 Photographic Exhibition of Murals in La Paz

Photographs of all the murals were brought together in an exhibition in the Casa de Cultura, La Paz.

Disabled people who had taken part in the work were invited to the opening event. They explained the messages illustrated in the murals to an audience of national and local authorities, NGOs, other disabled people, artists and the wider public.



5. Issues specific to certain groups

5.1 People living in rural areas

Some of the ways the situation for disabled people is even harder in rural areas have already been mentioned (see particularly sections 2.4 - 2.7). Medical services in rural areas are not only more inaccessible for disabled people, but, according to the CSUTCB (Rural Workers Union), the quality of care is worse “They have always practiced on peasants”. Similarly, the quality of education is said to be inferior, with teachers receiving less pay. The intention of the proposed educational reform bill is to equalize the situation.

A disabled person near Tupiza said, “There are more opportunities in town.” Indeed, a disabled person now living in Sucre talked of how much harder his life was when he was growing up in the country. He was isolated, did not know other disabled people and was unable to take part in the physical work of the country. It was only when he got to the town of Sucre that he met other disabled people and found work he could do. He describes arriving in the town:

“For me it was difficult to communicate with other comrades when I arrived in town. I saw many disabled people like me, some were already trained, others were trying to survive. For a disabled person it isn’t easy to survive. I tried to move forward with my own efforts, using my willpower and that of other people too.”

Disabled people in rural areas frequently have fewer opportunities than in urban areas. One person in a rural area talked of the lack of opportunities in the country:

”In the country it is more difficult, you have to work the land. We can’t do that, it’s impossible. In La Paz they can use mobile phones, at least there is that possibility, but here in the country we are like animals and that’s very sad for us. In the country you feel useless.”

He went on to expand on how useless he feels:

“We aren’t good for anything except watching the house, there is nothing we can do. I can’t work with an ox, I can’t dig the potatoes, I can’t harvest the barley, I can’t run, even if my son falls in the well I can’t do anything. It’s very difficult.”

It is very difficult for him to manoeuvre his chair across the cultivated fields as far as the road (see image below and full mural 4.2.6). Once he is there, few vehicles stop for him. It would be difficult for him to get to town, where there may be more work opportunities, or to find out what other disabled people are doing. He became disabled as an adult after he had work experience and education. But these skills and experience became irrelevant, as he is unable to get to a town where he might find work opportunities. Moreover, the

experience of disabled people in towns shows that, were he to get there, the chances of finding work would be low.

Difficulties in rural areas - Tiahuanacu



A disabled man in a rural community spoke of how the CSUTCB fails to take account of disabled people. As he put it, “I wish the confederation would take the needs of disabled people into account.” There are organisations for disabled people and for peasants, but neither fully considers the obvious overlaps. When interviewed about this issue, the President of the CSUTCB spoke of his readiness to have a section within the confederation for disabled people, but that the initiative must come from disabled people themselves and until now he says, “they haven’t approached us.” The difficulty with this is that disabled people, particularly in rural areas, often lack access to information and transport. As the same disabled person put it,

“I am not informed because I live here in the country... I don’t know if there are institutions that are responsible for disabled people or if there are organisations...I know absolutely nothing. I am here in the house, I can’t move more than a kilometer from my house.”

Even if disabled people were informed and able to get to meetings, high levels of discrimination combined with lack of confidence mean asking for representation would be difficult for many.

As one person put it,

“The reality for the disabled in the provinces is very sad. We people from the country suffer a lot. We can’t take part in meetings because it is difficult to get there, even with a wheelchair it’s difficult to get more than about a kilometer, because the path is difficult. So it is as if we were tied up here.”

Several specific impairment groups spoke of how the situation is worst in the most rural areas. For example, deaf people in rural areas rarely meet other deaf people or have a fully developed Sign Language. Few blind people have access to Braille teachers. As one blind person put it, “Visually impaired

people in rural areas have many problems.” Deafblind people talked of other deafblind people in rural areas being hidden away - they referred to it as “the ignored disability.”

In this research, it was significantly more difficult to find disabled people in rural areas than in urban areas. This is, however, largely connected with where disabled people are organized. Plan International staff in Guaqui spoke of how few disabled people they find in that area. They are about to start supporting a disabled people’s organisation in Patacamaya, where they say there are high numbers of disabled people. This may or may not be true but the person who set up the organisation there spoke of how, after his accident, “I didn’t know of any other disabled people, I thought I was the only one who used a wheelchair.” He decided to find out if there were other disabled people in the area, so he used radio to invite people to a meeting, “Disabled people came to affiliate themselves, people who were living hidden away like rabbits. Lots of people appeared when we started to organise ourselves. I never knew that there were so many disabled people. There are still many disabled people in rural communities that can’t come.” Only after the organisation was set up did it become apparent how many disabled people there are in the area.

5.2 Parents of disabled children

Whilst many of the priorities listed above were mentioned by parents of disabled children as well as by disabled adults, there are some needs specific to parents of disabled children that should be recognised.

The difficulties for parents of disabled children actually get worse as the child grows up. Many disabled adults complained that, although there are some organisations that provide help for young children, there is nothing for adults. This lack of support also applies to parents whose disabled children have grown up and now have nowhere to go. One father spoke of his stress, “Being with a deafblind person 24 hours a day is a special thing for the nerves.” Another said, “It’s stressful for the parents, they can’t rest.” Another said that “Parents need support. It’s too much to be 24 hours with a child that needs constant attention.” A mother described how she has to carry her child with her at all times. She has been told he may become autistic if left alone but things are becoming harder as the child gets bigger, “as a mother of a family I cook, iron, wash, there isn’t enough time.”

Many parents spoke of their need for help as well as for external places where their children can learn, socialise and, work, while parents do other things. Several spoke of their desperation, they asked for courses to learn how best to support their child. Many spoke of difficulties in finding other parents with disabled children. Parents also spoke of needing to leave the child in order to go out to earn a living. As one mother put it, “I am with her, I can’t work, there is no-one to leave her with.”

One mother of a 14-year-old girl spoke of her quest to get support. She has visited many institutions for disabled children but has been told that her daughter:

- Has the wrong impairment - “they reject her, saying she has another problem”;
- Is the wrong age - many more institutions exist for young children than for older children or adults (also see section 6.3.4);
- Lives in the wrong area;
- Has not been abandoned. According to a member of staff of one local NGO, if a child is abandoned it has some chance of getting support, but if the family wants to take responsibility for their child, it is very difficult to get help;
- Would have to pay for care, which the family cannot afford. A social worker in a centre for disabled people admitted that people from poorer families do not attend.

This mother’s priority is to get “support so that she can go out”. At the moment she cannot afford the medication her daughter needs and cannot leave her to go out to work. It is also difficult to go out with her daughter, who has regular fits and struggles to walk and to climb onto buses. This mother and daughter helped with the interviewing of a social worker at an NGO specifically working with disabled children. The mother was told she was not eligible for support as the child is too old and has not been abandoned. The social worker followed this by saying that if it is so difficult having a disabled child, the mother should not have had any more children. As in so many examples, disabled people and parents of disabled people are blamed for the difficulties they experience.

The mother of this girl had already tried to get support from a child sponsorship agency, but had been told the girl is too old. The girl’s brother is of an eligible age; his photo has been taken and sent to Europe along with 500 others in the community in search of a benefactor. If he is one of the lucky ones he will get funds, presents from the sponsor and access to free medical care. It will be up to him whether he shares the funding with his sister. Representatives of this NGO claim that it is no harder to find sponsors for disabled children than for non-disabled children, but they could not think of examples of disabled children with sponsors.

Parents in Tupiza talked of the abuse their children receive on the street and in school (see section 2.3.1). Two parents of disabled children who are also teachers spoke of the difficulty in meeting their children’s needs in the classroom, where there are 30 other children demanding attention. Sometimes the disabled child gets angry because no-one can understand him. He then hits other children, which results in him being isolated. Parents spoke of the urgent need for someone to give their children the attention they need at school. Some thought the only way to get this would be in a special school. But others spoke of their wish for their child to be included with other children.

If the stories of how many disabled children are hidden away are true, then the parents who took part in this research are unrepresentative. One mother said, "we don't want our children to live in a corner of the house." The parents who took part in this are self-selecting to be among those who agree with this sentiment. By definition, it is hard to find examples of those that hide their disabled child away.

6. Who represents who?

Roles and responsibilities of organisations that currently claim to support disabled people

It became apparent during the course of this research that there are many organisations that have substantial funding to work on behalf of disabled people, and in so doing claim a representative role. Many disabled people question the legitimacy of this role. The topic of representation deserves more consideration.

6.1 Who represents who?

On several occasions during interviews of staff of NGOs or local authorities the researcher was referred to organisations **for**, but not **of**, disabled people for more information. Indeed this was frequently given as a reason why the organisation being interviewed did not consider the needs of disabled people. When trying to get an interview with local authorities, the researcher was frequently told to contact Codepedis instead, as they are the ones that do disability work.

The researcher was also asked for advice as if more of an expert on local disabled people's needs than the people themselves. The idea that disabled people in the local area are the experts as to their own needs and priorities was anathema to almost all the non-disabled people interviewed. In contrast to this, a disabled person in a focus group pointed out:

“We know how we live, I live 24 hours a day with disability. Who could know more than me? No-one, not even my wife, knows more about my disability because no-one can say what I feel. Everybody here is disabled; no-one can understand that as much as the person who lives it. Therefore in order to do any project, budget, who should be asked? Not the Mayor, but ourselves. We should be asked what we need”.

The local council in Santa Cruz held a series of consultation days, the stated aim of which was to enable different groups to participate in determining budgetary priorities. The process was funded by USAID. The meeting for NGOs was in a smart hotel with a choice of menus for the 3-course lunch served by waiters. The meeting to consider disability took place within the department of education building. The lunch was much simpler, with no choice of menu.

Non-disabled people working in organisations **for** disabled people outnumbered disabled people in the meeting on disability issues. There was some conflict in this meeting with many people questioning the purpose, referring back to previous meetings with similar discussions. A large part of

the day was spent in small groups discussing 'the priorities of disabled people'. No distinction was made between the opinions of disabled people and non-disabled people. Indeed in the group that the researcher was in, there was only one local disabled person. He reported his priority to be food and housing. This view was over-ridden by non-disabled members of the group who said that disabled people should move away from this 'welfarist model'. The non-disabled person, who reported back to the larger group, claimed the priority was for the government to provide staff for institutions for disabled people and a census to count the numbers of disabled people. No mention was made of the need for food and housing.

After the meeting, the organiser talked of how difficult it is to get disabled people living in institutions to take part. She said on several occasions she had invited them to come, but it is always the staff that attend. In her view this makes the work more difficult "you don't speak directly to disabled people. I believe institutions take the voice away from disabled people". A non-disabled staff member from an NGO working with disabled people was later interviewed. She complained that as a non-disabled person in this meeting she had been discriminated against: her right to represent the disabled people she works with had been questioned. There is clearly confusion as to who legitimately represents who, as well as what discrimination means.

Staff of institutions complained that associations of disabled people do not include the severely disabled people who come to their institution. From the observations of this research there may be some truth in this. Those with the most severe impairments, who also experience the worst discrimination, were not seen taking an active role in disabled people's organisations. It may be that isolation and discrimination lead to lack of information, transport, and confidence to take part in meetings. Those who dominate the organisations are - perhaps inevitably - those who either developed some skills and confidence prior to becoming disabled, or who experience relatively little discrimination. Whilst this may be the case, it does not follow that staff of institutions for disabled people automatically represent their clients. Only if there had been discussion and freedom of choice would such representation be credible.

Disabled people in all areas where these institutions exist complained of the lack of control, employment or representation of disabled people within the administration. In Santa Cruz, Sucre and Montero, disabled people complained of how organisations had been set up for disabled people but, once the funding had been established, the organisation was taken over by non-disabled people making a living. Only in focus groups in more rural areas, where there are no institutions for disabled people, was this not referred to.

In Montero, an association of disabled people stressed that,

"a centre created for disabled people should be administered by a disabled person...In this centre, which is said to be for disability, not even the person who sweeps up is disabled. Because of that, I say these centres have been created for personal interests".

6.2 Associations and federations Of disabled people

Among those associations of disabled people that took part in this research, few had any external funding. Many had no meeting space, no office furniture or equipment, no means of circulating information other than word of mouth or sympathetic radio channels, and certainly no funds to pay for refreshments or travel costs.

Many complained that attendance at meetings would be higher if people could at least be reimbursed their travel costs. Poverty and transport problems keep many away from meetings. People living in isolated areas are less likely to find out about meetings or to be able to make the journey. Many disabled people expressed huge levels of determination and commitment to overcome barriers in order to get to meetings. But those living more centrally almost inevitably dominate meetings. The research observations would indicate that people in urban areas tend to have more educational, and employment opportunities. In these areas, the work of associations is more strongly focussed on equal rights to, for example, employment and transport. In rural areas the focus is more commonly on basic needs, such as food, clothing and shelter.

The association of disabled people in Tupiza were running a campaign during the research process to get donations of chairs and tables for their meeting room. The local authority had loaned the unfurnished room. An association of disabled people in Montero used a member's courtyard as a meeting space but were trying to find funding for office equipment. The association of deaf people in Sucre meet in a member's living room.

Meanwhile, organisations for disabled people such as Codepedis and NGOs have equipped offices with at least some level of regular funding and paid employees – few of whom are disabled people. Their funding generally comes from the state, international NGOs and, in the case of institutions such as Fusindo and Teresa de los Andes in Santa Cruz, they also receive funding from business. It is hardly surprising that there is conflict and resentment between organisations **of** disabled people and the funded organisations **for** disabled people.

NGOs appear reluctant to deal directly with disabled people's organisations, yet these are the only organisations that have any legitimacy as representatives of disabled people. They could actually deal with the daily concerns, as expressed by their members. Many disabled people talked of the support they get from other disabled people. One person expressed the gratitude he feels towards other disabled people:

“I used to be in a dark place, I didn't know how to get out. I give thanks to my comrades who encouraged me with different ideas. In this way I could train myself, put myself on a level with others. In this way I also got to know many comrades who were disabled like me. Even now I

see some people who need moral support and I believe these people need encouragement in the same way as I was pushed.”

This person now has his own business and is able to financially support his family. In his view, the priority is for a building where people can meet to exchange experiences and support each other. In this way people could work out how best to move forward.

Difficulties between organisations **of** and organisations **for** disabled people are widespread. At the congress of the National Federation of Blind People in Potosi in July 2006, representatives of the *Instituto Boliviano de Ceguera*, (a state funded organisation **for**, but not exclusively **of** blind people) presented ideas to put to the educational congress regarding teaching in Braille. During discussion of these plans it was revealed that the IBC was not planning to send a single blind representative. After lively discussion with members of the Federation it was agreed to change plans and send blind representatives.

A few international NGOs that took part in this work do support organisations **of** disabled people. Sense International supports organisations of deafblind people. Plan International is committed to supporting an organisation of disabled people in Patacamaya, to set up a rehabilitation centre. This centre may be what this particular disabled people’s association would like, but it is also a conveniently distinct project for NGO funding. The support that is being offered is in terms of expert medical personnel. This does not require major reconsideration of aims and values, as would a focus on equal employment of disabled people for example. The director of the department supporting this organisation is a disabled man, who talked of his commitment to working on disability issues.

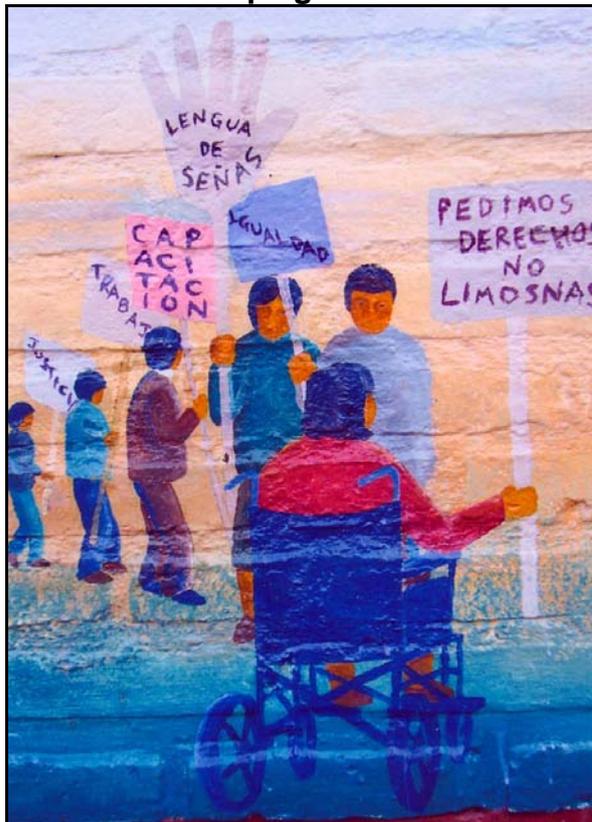
From the observations of this research, it appeared that the area with the least conflict between Codepedis and the associations of disabled people was Santa Cruz. It was also the area with the strongest federation, relative to Codepedis. Members of the federation in Santa Cruz claimed that the reason for fewer problems between the organisations there is that, “the associations are stronger” and so are more able to assert their needs. It may be coincidence but it appeared from this research that the strongest, most active Codepedis was in Sucre where the Federation is fragmented, with some members complaining they were not even aware of the Federation’s irregular meetings.

On August 6th, in Santa Cruz, the Associations organised parades as part of the national Independence Day celebrations. Indeed, in a meeting of the Federation after this, those organisations that did not take part were asked to justify themselves. In Sucre the parades were of greater significance with international heads of state attending, as the event also marked the opening of the assembly to rewrite the constitution. No organisations of disabled people were seen in the parade. Whilst Codepedis may be a strong organisation in Sucre, it is not a people’s organisation, so there is not the motivation to demonstrate. In Sucre, more than in other places, local

government officials tried to excuse their lack of knowledge and inclusion of disabled people by saying disability is the job of Codepedis, and not their job.

In Santa Cruz, local authorities appeared to be better informed as to disability issues. The official consultations with disabled people may have been ineffectual but indicate more consideration than in other areas. In Santa Cruz the Federation is sufficiently organised so that if disabled people do not like something they demonstrate. Their tactics include, 'blockades and serenades' (in which people assemble outside the home of a person they are trying to influence and sing to them at night until that person agrees to listen to their demands).

Santa Cruz campaigners.



The campaigns appear to have had results. According to a member of the Federation, "now authorities take us into account, it didn't used to be like this. Two years ago the local council didn't talk about disabled people". According to members of Cobopdi, only in Santa Cruz and Trinidad do the local federations have any funding of their own. In Santa Cruz, the Association of disabled people has its own office - funded by running a local public convenience. There are also a couple of houses in which disabled people live together. As people in other parts also verified, housing is a major problem for many disabled people.

6.3 Organisations FOR disabled people

6.3.1 Conalpedis and Codepedis

During the research period there was ongoing conflict between Conalpedis or its departmental organisations Codepedis and associations or federations of disabled people. A large part of this conflict is considered to come from the fact that whilst Conalpedis and Codepedis are state-funded (albeit meagrely), and some branches also get support from international NGOs; organisations **of** disabled people rarely have their own office space, equipment or resources of any kind.

As was pointed out in different focus groups, Conalpedis and Codepedis are not organisations of disabled people. One disabled person said a major cause of the conflict is that Conalpedis and Codepedis employ non-disabled people. He complained that, 'the biggest problem is lack of employment' and that even these organisations were not setting an example on this issue. There is no credibility in pushing other organisations to employ disabled people, if they do not even do so themselves. As referred to in section 2.9, in one case the office of Codepedis moved from a physically accessible building to one up a flight of steps with an entrance too narrow for some wheelchair users.

Conalpedis and Codepedis were set up by the law with the principal objectives of, "orientation, coordination, control and assessment of policies and actions to benefit disabled people". When members of the Federation in Santa Cruz were asked about the relative functions of Codepedis and the Federation, they were quite clear:

- "There are well defined differences between the Federation and Codepedis. Codepedis exists to execute the law, to ensure compliance with the law, that's all";
- "If Codepedis is supporting and complying with its function - the law - that's fine. But the Federation needs to question Codepedis";
- "Codepedis can't go to the Federation and tell them what to do, but the Federation can question Codepedis";
- "If there were no Federation, Codepedis would not function, there are representatives of the Federation on the directorate."

The associations are people's organisations, "where people get together to try to improve the situation for the members in similar situations. The associations can give us a lot. If an association has problems it goes to the Federation which exists to support and solve conflicts of the associations." As one person put it, "the strengthening of the Federation is important regardless."

Codepedis on the other hand is a state-funded public organisation set up to support the needs of disabled people but not to lead. "Codepedis has wages and works through the local council. For that reason, it has more resources." Codepedis has a lot of resources relative to associations that have nothing,

but very little relative to other parts of local government. It has "the smallest budget of the council" and as one civil servant put it, "the council does not give it importance."

The expectations that disabled people have of Codepedis staff were often unrealistically high. In one Federation meeting, the paid staff of Codepedis were told they are paid and should therefore be prepared to work 24 hours a day. In Tupiza, a smaller town with less access to organisations such as Codepedis, the director of Codepedis was perceived to have so much power he could sort out any problems if he chose. The local association also complained that Codepedis did not understand their needs. One morning Codepedis staff arrived unannounced with 10 wheelchairs. These could have been useful, but as there was no warning, nowhere to store them nor any list of people needing them, they were given to the first 10 people asking for them. Several months later some people were not using the chairs but were keeping them in case they might become necessary. Meanwhile, a teenage girl came to a meeting in her mother's arms. She could not walk and had no form of mobility aid. Carrying a small child in this manner may be possible, but as the child grows up it becomes increasingly difficult.

In many ways it seems the establishment of Conalpedis and Codepedis was a Pyrrhic victory. They easily become seen as the source of expertise for local and national authorities rather than more representative disabled people's organisations. One local civil servant believed that Codepedis should ignore the conflict with associations of disabled people. To her Codepedis is the more credible body, despite its lack of representation. The department of social development in Sucre talked of the need for Codepedis to be visible in each municipality so that disabled people would know they are not alone. This would be more convincing as a reason for organisations **of** disabled people to be visible in each municipality.

Conalpedis and Codepedis may increase the common perception that disabled people are incapable of managing their own affairs or representing themselves. People in a focus group in Montero complained, "we don't want intermediaries."

When the President of Cobopdi heard that International Service were planning to place foreign 'development workers' within Conalpedis and one office of Codepedis, he was incensed, "I don't understand why they want to support Codepedis - it already has state funds. It is a state institution, not an association **of** disabled people." Meanwhile, in his view, the reason for the weakness of the federations in many parts is that, "they have no funds. There is no money, that's why there aren't associations." Funding Conalpedis and Codepedis increases the division between them and the organisations **of** disabled people, "when there is a weak organisation, another becomes more prominent." He went on to say that the only legitimate representatives of disabled people are the associations and federations of disabled people. He asks why it is so hard for these associations to get funding. Why do so many NGOs prefer to fund organisations **for** but not **of** disabled people? "The

federations and the associations need funds. It is mistaken to support Conalpedis and Codepedis.”

International support for public agencies **for** disability is clearly contrary to the expressed priorities of disabled people, in both rural and urban areas, to have jobs and to be listened to without intermediaries. Whether or not Conalpedis and Codepedis specifically claim this role, their strength, relative to associations, means that these state bodies are frequently perceived by non-disabled people to have representative status. On several occasions during this research it was difficult to get local authorities to agree to an interview. They insisted if the work was on disability then Codepedis should be contacted not the department of education or health or wider administration.

For all these reasons there is resentment from associations of disabled people towards these state organisations.

6.3.2 Instituto Boliviano de Ceguera (IBC)

A similar situation exists between the Instituto Boliviano de Ceguera and the Federacion Nacional de Ciegos de Bolivia (FENACIEBO) as between Conalpedis and the Federations of disabled people. The directorate of FENACIEBO is wholly made up of blind people, although some sighted people may help with the administration. It does not allow members who are part of institutions. The Federation functions like a union, working to improve the lives of its members. The IBC on the other hand is not a membership organisation; it is not run by blind people, although there are some blind people working there.

FENACIEBO is clearly the more representative of the two bodies. But the IBC has more funding and has some employees provided by the state. It also receives more international recognition than does FENACIEBO. Indeed, International Service, the NGO commissioning this research decided after this research had finished to appoint a development worker to help the IBC, not FENACIEBO.

6.3.3 Non-governmental Organisations (NGOs)

There has been mention of the role of NGOs in many sections of this report. Several of the NGOs that were interviewed claim to represent and work for disabled people’s needs, but disabled people criticised their work perhaps more commonly than anything else. Several disabled people were asked for examples of NGOs doing positive work in Bolivia and could not think of any⁷. As one leader of a Federation put it, “they are all making money out of disabled people”.

As described in section 2.3.5, there is little employment of disabled people even within those NGOs that claim to work with them. It was observed that

⁷ This does not of course prove that none exist

many more NGOs work with children than with adults and this was verified in numerous focus groups, where disabled people complained of the lack of provision for adults. When the leader of a Federation of disabled people's organisations was asked about this, he responded without hesitation that this is because "children don't demand their rights."

NGOs appear to like working with children, but the needs of disabled adults are frequently higher. A policeman, referring to a disabled woman who wanders the street with nowhere to go, said, "if she were a child it would be easier, but she is 35-40 years old." The teenage girl referred to in the previous section, who is carried in her mother's arms, is in a more difficult position as she grows up than she was as a small child. Parents of disabled children talked of the difficulties they face now, but the big worry many kept referring to, is what happens when the children grow up and their parents are gone. As one parent put it, "my daughter is 31. I am already old. I could die at any time and my daughter would be left helpless. We need a hostel where they could be well looked after."

The director of an institution for older people, reported that they do not have many disabled residents. She did recognise that there is little support for disabled adults and that it is "easier for children. There is nowhere for adults suffering (sic) from disability." They have one disabled 32-year-old living amongst the old people. One small group of parents of children with Down's syndrome talked of not knowing any adults with Down's. They suggested this is because there is nowhere for the adults to go, so they stay at home.

Parents complained that their deafblind children are offered minimal education until they are 12, after which there is nothing. Some deafblind adults do handicrafts at a centre for people with visual impairments, but one participant, who is totally deafblind, has nowhere to go. Furthermore, basic observation showed lots of adults wanted to hold and care for a deafblind two year old, but a deafblind adult got very little attention. A member of staff at an institution for disabled children said that the reason they only accept new children younger than five, is that these children "are the most unprotected." When the validity of this was questioned with another member of staff, a different story was told. According to this social worker, older children "already have established ways of behaving, they may have had sexual experiences and we don't know where they have been". Working with young children is clearly more attractive to many staff of NGOs, but this has no relation to who has greater needs.

It seems that ease of work together with staff and funder satisfaction, come above needs of supposed 'beneficiaries' for many NGOs. At the entrance to one institution for disabled children, there is a plaque that reads, "blessed is he who cares for the poor and the cripple, on judgement day the lord will liberate him".

Motto on a rock at the entrance gate



What the '*poor and the crippled*' want does not seem to be considered - let alone why they need help. When a member of staff of another NGO was asked why they had chosen to prioritise disability, the response was that the funder had called for it. The question of whether what they offer is wanted by disabled people again appeared not to have been considered.

Many NGOs seem ignorant of how severely they are criticised. Indeed, it is difficult for them to find out. If an NGO controls resources, potential beneficiaries are likely to say what they think the NGO wants to hear. The same barrier, of course, applies to this research - people only started to criticise NGOs once it was clear that there was no potential funding related to their contribution. Despite criticism of NGOs coming up many times in the mural designs, when it came to the opening event, disabled people were reluctant to explain these messages in public.

As part of this research, a meeting was attended between an association of disabled people and an NGO in Tupiza offering to start a centre **for** disabled people, employing non-disabled 'experts'. The association had not mentioned that this was a need despite several opportunities prior to this encounter with a potential funder. The non-disabled staff of this NGO described what they want to do **for** disabled people. The NGO staff largely ignored the two local disabled people who had accompanied the researchers and everything was directed at the foreigners. When asked where the ideas came from, the NGO staff even appeared proud to say they had made up the project themselves. There was no pretence that it was in any way based on what disabled people

had asked for. But the two members of the local disability association finished the meeting by welcoming the offer of help, with no mention of the various other priorities they had spoken of during the research process.

In a similar way to the criticism of funding Conalpedis and Codepedis, if NGOs insist on funding organisations **for**, but not **of** disabled people, the result is that the funded organisations are increasingly seen as the efficient well-established organisations at the expense of associations of disabled people.

One civil servant criticised the nature of support from certain NGOs, saying it is a way of buying the acquiescence of disabled people,

“I pay your transport or I give you some food and whether you like it or not, you have some level of loyalty to me... levels of poverty generate this clientelism. For example, this NGO controlled many disabled people in this way, paying for transport or food and disabled people are happy to get the help.”

Meanwhile, according to this person and to numerous disabled people, the staff of NGOs are paid huge salaries and live luxurious lifestyles by getting international funding to support disabled people but in reality for their own benefit - while disabled people's real priorities are ignored.

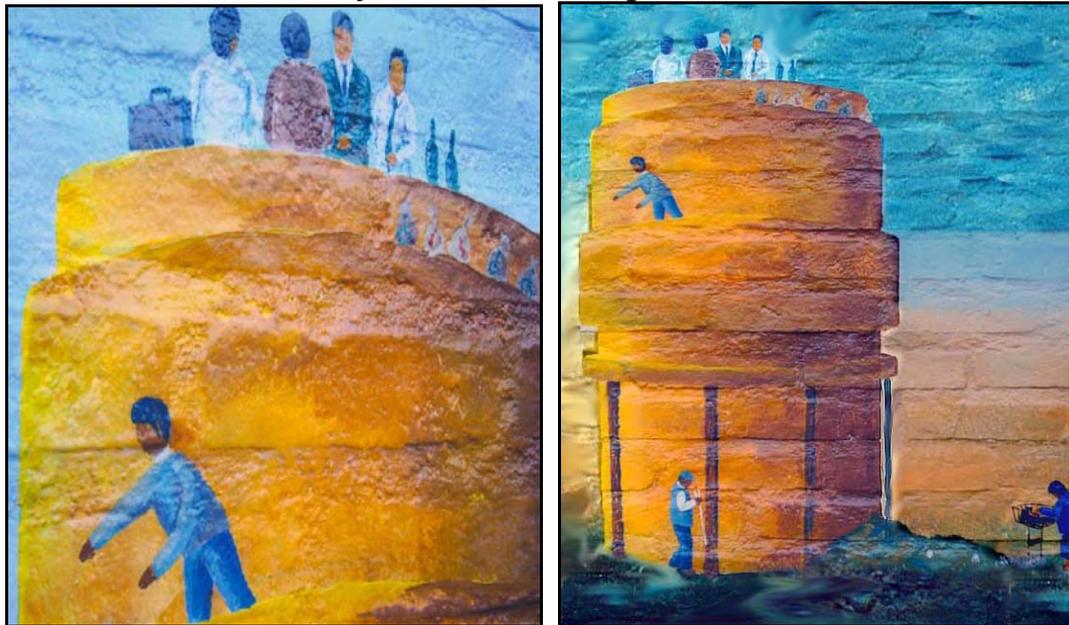
Criticisms of NGOs were stronger in urban areas, perhaps because disabled people are better organised and more aware of their rights, and also because they have more knowledge of NGOs. The murals in Sucre and Santa Cruz contain strong messages against NGOs. In the Sucre mural, money can be seen raining onto Bolivia, but NGO staff take the money to build their own city where the trees are still green and the rivers still have water (full mural 4.2.1).

Resources taken for rich people - Sucre mural



In the Santa Cruz mural, NGO staff sit on top of a tower, which has neither steps nor ramps. They are surrounded by bags of money designated for disabled people, but the staff sit drinking wine. During discussions over this mural design, one person criticised another's idea, saying some staff of NGOs are trying to help, he therefore drew a person reaching out to the disabled people down below, building a school, cultivating the land and organising for their rights. However, the distance is too great, this NGO worker is physically and culturally too far removed from the lives of disabled people to be able to reach (see below and full mural 4.2.5).

NGO and local authority workers drinking wine on tower - Santa Cruz



It cannot be coincidence that in rural, more isolated, areas there was little if any mention of NGOs. When specifically asked about their experience of NGOs, one person in Tupiza responded, "Of NGOs, no, I don't have much knowledge, perhaps they aren't interested in us." As one person who previously worked in an NGO put it,

"NGOs could base themselves in the country and start to develop their activities there, but they won't do that because it is more comfortable working in the city, of course it is much more comfortable. Why live in the country?"

People living less isolated and somewhat more privileged lives in urban areas have far more experience of the work of NGOs. Among these people criticism was rife.

Comments made by disabled people regarding NGOs

- “They are taking advantage of us, disabled people and poor people”;
- “They are making money out of us”;
- “They are living off poor people”;
- “NGOs are not interested in people, they are more interested in their own needs”;
- “They think we are objects. They take photos of us and use them to justify their work”;
- “They are doing a lot of damage to the Federation...they are sighted people” (a blind man describing an organisation that works with blind people);
- “They are not here to help anybody, they are here to integrate the most vulnerable into the process of globalisation”;
- “Nobody controls these centres supposedly for disabled people”;
- “Many NGOs live off disabled people”;
- “These NGO projects help their own organisations more than they help disabled people”;
- “The state prefers to provide staff for these NGOs rather than to disabled people”;
- “NGOs do not employ disabled people, but a non-disabled person is not the same as a person who lives disability 24 hours a day”;
- “How can they say they are non-governmental when they get money from the state? They are state organisations. They can’t say that they don’t depend on the state when they need money from the state”;
- “Teresa de los Andes gets money from the state, from people who give donations and from the town council – but this money does not go to disabled people, instead it goes to the organisation”;
- “NGOs like working with children, because children do not demand their rights”;
- “I know an NGO with lots and lots of money in the name of disabled people but it does very little for disabled people”;
- “The only thing that has been achieved by the methodology of these NGOs is to make the staff rich... they have no reason to worry and they speak well in the name of disabled people”;
- “They don’t want to change this because they feel that they are doing many things for disability, but they aren’t doing anything, they are just benefiting themselves”;
- “Whatever person comes to do a project takes lots of photos, gets their results and the beneficiary is the intermediary. They say it’s for disabled people, but when will it arrive? We don’t know, how much do they spend? How much do they pocket for themselves? I believe the time has come for us disabled people to be the direct beneficiaries without intermediaries”.

Several members of NGO staff were also outspoken in their condemnation of their organisation’s own work (see quotes below). Without exception these

people insisted on anonymity. More than one person talked of fear for their job if their comments were attributed to them.

Comments made by NGO staff, civil servants and others

- “NGOs are here to appease the consciences of the rich and maintain the status quo”.
- “NGOs are not here to do anything against poverty. They have just constructed the new rich”;
- “This NGO uses the name of disabled people. In other countries they say ‘look we have made an alliance with this confederation of disabled people’. I imagine that in Europe they think this NGO really works, therefore the money comes raining in. As far as I know this NGO manages between \$200,000-\$250,000 annually”;
- “Just imagine this woman, director of an NGO, earns \$20,000, she earns more than the President”;
- “All NGOs are spongers off poor people, churches are the worst”;
- “NGOs are here to maintain relations of poverty”;
- “NGOs think they are independent republics”;
- “NGOs are the strategy that is used by rich countries to maintain their wealth”;
- “The strategy of NGOs is to develop personal benefits, it is a way of money laundering. They don’t have to pay tax”;
- “NGOs use disabled people to get money out of other countries”;
- “Some NGOs control disabled people. They give a little economic help so that these people do not criticise what they are doing”;
- “You shouldn’t trust anything that NGOs tell you”;
- “International cooperation is here to drink good coffee. They don’t do anything useful”;
- “International cooperation is good business”.

If NGOs want to improve the way they are regarded, they will need to find ways of hearing and responding to the levels of criticisms that exist.

6.3.3 Other institutions

On many occasions, disabled people in focus groups, as well as several non-disabled interviewees referred to suspected corruption in institutions for disabled people. Nobody has the power to insist on an audit of these organisations, but many people complained that, “money does not reach the most vulnerable, on the contrary they are the ones who receive the least.” Non-disabled people control all the institutions that were encountered, whether funded by NGOs, the church, multinational organisations or the state.

A couple of institutions were visited where disabled people live for most or all of their lives. These places are for people who have been abandoned for whatever reason. The old people’s home in Tupiza was the focus of envy among the group of blind people, as already described. This is despite the fact that people reported not being able to leave the institution to go into the

outside world for months at a time. There are disabled people who were abandoned there more than 25 years ago. One of the residents of the institution reported that:

“There aren’t many staff to take disabled people out. Sometimes one feels locked in here. Some disabled people have been here for many years. Here you get all your food, your clothes, but they can’t go out when they want. Those that have families go out sometimes. But those that don’t have families go out about once a year.”

The Hogar 25 de Mayo in Sucre is an institution for people who have been abandoned; it includes many disabled people and is very over-crowded. One disabled woman, who has lived there for 57 years, said when interviewed in June, “Sometimes I go out. For example I went out into the street one time in February.” When she arrived, there were 35 women, now there are 115. Apart from that, she says, nothing has changed since she arrived. People are found abandoned in the porch on a regular basis. More women than men arrive at the institution, but, as there is no space in the women’s wing, they are turned away. People arrive who have nowhere else to go, many have been living on the street, and “the majority arrive in a terrible state When they arrive they don’t understand any more. They are very dehydrated and they can’t eat much.”

In Tupiza, the disabled people in the old people’s home complained that in contrast to the old people there, they get no state pension. Several have been there for more than 20 years, but they get nothing because they are not old enough. The director of another institution primarily for old people talked of disabled people’s needs being, “a home where they can be looked after. They need somewhere to spend their time and feel useful.” The same person reported that, “many disabled people come here and beg to come in but that isn’t our goal.”

The director of the *Hogar 25 de Mayo* talked of how little attention any government pays to those who have been abandoned by society. As is quoted at the front of this report, she describes how the current government may talk a lot about working with poor people, but it does not consider the needs of those that have been truly abandoned by society. Governments of all kinds need to take action that will get them support and helping the poorest most rejected people, does not get support: “Those that need most are those that speak least.”

6.4 Government and Political parties

Election observers in Sucre from the *Organización de los Estados Americanos* for the constitutional assembly elections on July 2nd 2006 offered to take note of any access issues for disabled people. They also asked their colleagues covering the whole of the department of Chuquisaca. None of them had been aware of any disabled people voting although they did report having seen provision for blind people to vote. Whilst it is certainly not the case that no disabled people vote, the reality is that many polling stations are

physically inaccessible to people with mobility impairments. Voting is compulsory and evidence of having voted is needed for official business such as bank accounts and public sector salaries – but it may be that these services are not widely used by disabled people. Also many participants in focus groups talked of disillusionment with all political parties and governments. Some said that political parties often promise help to disabled people during the election period, but once they are elected, there is rarely any help forthcoming. As one person put it, “governments are not going to do anything if we don’t demonstrate. Now the government acts as if we did not exist.” Blind people in Tupiza did talk of how difficult it was to meet their legal obligation to vote. A blind woman in Tupiza talked of having to pay someone to help her.

There were several reports of both national and local authorities giving more attention to disability now than in the past. In several areas, local authorities were starting to allocate more funds to disabled people. In Patacamaya, the rehabilitation project organised by the Federation of disabled people will receive some local authority funding.

Ramiro Delgado, from the *Vice Ministerio de Co-ordinación con los Movimientos Sociales*, in the *Ministerio de Gobierno* was asked what has brought about the apparently increased profile of disability. He replied,

“The demands that come from disabled people, but also the decision of this government to work on social inclusion. The first thing we have done is to raise the National Plan of Equality of Opportunities to the status of Supreme Decree. The state is taking responsibility for putting the theme of disability on the public agenda.”

The current government officially recognised the *Plan Nacional de Igualdad y Equiparación de Oportunidades* and organised seminars to disseminate it. Letters were sent from the Ministry of Government to other Ministries calling for them to incorporate this plan into their annual budgets. The government also appointed people with specific responsibility for disability in several ministries.

The introduction to the *Plan Nacional de Igualdad* recognises that the majority of disabled people:

“find themselves in situation of inequality, excluded and in conditions of poverty. They are victims of discrimination in different aspects of social life.”

It goes on to say that disability has many causes,

“in the majority of cases it is caused by the high social costs associated with poverty... the noxious effects of the market economy and economic growth, based on the priorities of capital, increased individualism and consumerism without limits, promotes environmental contamination with damage to the environment and to human health.”

Later it refers to the actions that have been taken up until now as being insufficient, not providing appropriate solutions to the scale of the problem and maintaining disabled people “in the hidden margins of society.” The plan contains sections relating to social and legal rights, education, health, housing, work, access, self-determination and participation. There is a high level of recognition of the discrimination inherent in the current system. However, at the end of each section is a list of ‘*organismos ejecutores*’. There is no distinction made between organisations **of** and **for** disabled people. Both come towards the bottom of the list. Even the section on self-determination has ‘*organisations of and for disabled people*’ at the bottom of the list of executors. Conalpedis and Codepedis head the list, but there is nothing to say that those responsible in any of the 12 organisations listed have to be disabled people.

It is highly questionable whether this government would put indigenous people so low in the list of executors of a plan of action on behalf of indigenous people. Yet, for disability, it still seems to be widely accepted that non-disabled people can legitimately act on their behalf.

6.5 Social movements

Bolivia is famous throughout the world for the strength of its social movements. Indeed these have brought down several governments in recent history. The extent to which disabled people are included in these movements is debatable. It seems that, generally, disability is seen as separate from every other concern or identity a person may have. As described in 5.1, the Rural Workers Union (CSUTCB) does not currently do any work with disabled people who are also ‘*campesinos*’. One disabled man in a rural community suggested interviewing the president of this confederation, in order to suggest including the needs of disabled campesinos: “although we are invalids our families also need resources, they work too, we should not be isolated, we should be included...”

At present there seems to be little consideration of disabled people as farmers, indigenous people, women, old people. When people in focus groups were asked about the discrimination against different groups, it was rarely recognised that disabled people are among all these groups: “there is always discrimination against people in the country, against women and worse against disabled people.” It is as if someone cannot be a woman, or someone from the country as well as being disabled. One disabled woman did mention that as a disabled person she feels her sexual identity is unrecognised. As in the example of the wheelchair user in a rural area (see section 5.1), there are organisations of *campesinos* and of disabled people but little overlap between the two. It is as if being disabled is enough identity in itself without also being a woman, an indigenous person, an old person or an agriculturalist.

7. Wider issues affecting disabled people

The same issues that affect other people also affect disabled people. Being among the most isolated, disabled people are often among the most vulnerable to other factors. Some examples of factors affecting disabled people and other people in Bolivia are as follows:

7.1 Migration

In the areas around Tupiza, Guaqui and Yotala near Sucre, there were noticeable numbers of empty houses. Migration from rural to urban areas is common, as is migration to Argentina, Spain or the US, where employment prospects are perceived to be greater. Several examples were heard of migration taking place and disabled people being left behind. In the Hogar 25 de Mayo there was a disabled woman who had lived there since her family migrated to Argentina when she was a teenager. According to her, they had not been able to take her with them, so had left her in the institution. In Taraco, a disabled woman said there are not many people left in the village, most have migrated, and there are lots of empty houses. Disabled people are rarely able to leave.

There were many unverified rumours about two disabled people who have been left in a village near Tupiza, whilst all the rest of the community have migrated. The rumours are that because of a local mine, “there is no water left in the community” and the earth is contaminated with heavy metals. The other inhabitants had no choice but to leave, but two disabled people who were not able to make the journey were left behind. They now survive by begging by the side of the road.

7.2 Climate change

In some areas, the soil has been left infertile through mining and, in others, through lack of rain. Drought may be due to rivers being diverted and dammed or may be due to climate change. Several people told stories of their childhoods when the rivers ran full. This is depicted in the mural in Sucre (see section 4), where it was said that natural resources such as water had been diverted to meet the needs of cities, whilst the countryside becomes parched. This has also contributed to the migration described above.

Some disabled people also blamed the practices of NGOs for this situation. One person talked of how international NGOs in his home village had introduced high-yielding crops that required intensive irrigation. This diverted water from the rivers and made people dependent on the NGOs for further input. It was also said that the luxurious lifestyles led by international NGO workers used excessive amounts of water. This is also depicted in the mural in Sucre (see section 4.2.1).

7.3 Access to Water

Bolivia is internationally famous for its successful campaign against privatised water companies. Those involved in the campaign for access to water for all say that they will work with all sectors working against water privatisation. But in a similar manner to the CSUTCB, they do not work with any disabled people's organisations, as they do not know of any involved in the campaign. In the course of this research, the researcher did not find any disabled people's organisations involved in this wider campaign either.

Meanwhile the Suez water company, with its local branch '*Aguas de Illimani*', reported doing nothing to ensure their water supply was physically or financially accessible to disabled people. Their representative said that "We just make connections, we aren't a social organisation." She described how they have different tariffs for water: institutions for disabled people would only pay the domestic rate, not the commercial rate. This was said as if it constituted a charitable donation. She went on to report that they give money to street children through a charity Luz y Esperanza. This water company left Bolivia at the end of 2006.

7.4 Poverty

Many NGOs claim to work to reduce poverty, although on further discussion some staff recognise that their work does nothing towards this goal. When an international NGO was questioned as to their focus on children, the response was that "children are the future." When the same person was asked what the NGO is doing to tackle the causes of poverty, he responded, "We know that the causes of poverty are structural. We can't change the causes, in practice it isn't like that." He also agreed that, unless the structural causes are addressed, children will grow up into a world with at least as much poverty as exists at present. Many NGO representatives responded to the question of the causes of poverty by describing their projects, for example providing a doctor, a school, or irrigation system. Only on further questioning would people say that the need for these projects is a symptom of poverty, not a cause.

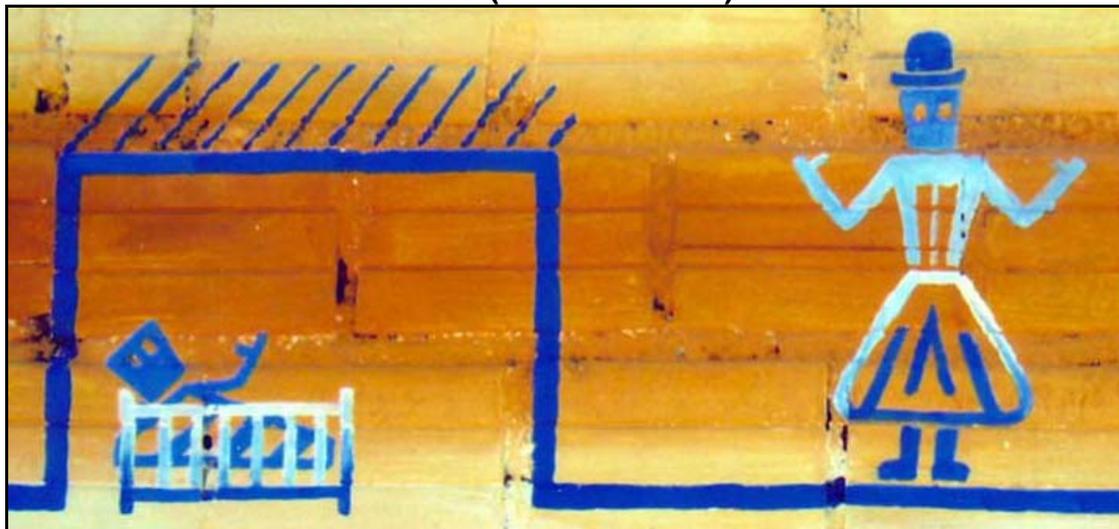
A senior member of staff of an international NGO described how his organisation has to act in a manner consistent with the British government's supposed policy to eradicate poverty. He went on to say, "but in reality anything can be justified as an eradication of poverty." From this research it is unclear what this NGO does towards eradicating poverty of disabled people or anyone else (see quotes section 6.3.3).

The connection between disability and poverty is often repeated. As one member of the government said, the causes of poverty need to be addressed, "We know that disability is associated with poverty. Poverty is fuelled by unequal distribution of resources...30-40% of people in this country live in extreme poverty. We must think about public policies that benefit the whole population, not only disabled people."

Parents of disabled children talked about the inevitable poverty resulting from needing to be with the child 100% of the time. Disabled people themselves talked about the poverty resulting from lack of access to a pension, employment, healthcare and education.

In some cases the distinction between the effects of poverty and the effects of disability are unclear. For example, in Tiahuanacu, the *Defensor de Pueblo* took the researcher to visit a disabled child in a rural community. The child's father spends all day fishing in the lake to earn a living, while the grandmother, who is partially sighted, cares for the child. The child lives in a cot, and is unable to speak or stand. It is unclear whether this child's needs are vastly different from those of any other child living in poverty. According to the *Defensor del Pueblo*, this child needs to be taken to a rehabilitation centre in La Paz, but there is not funding to do so. It may be true that a rehabilitation centre could help the child learn to walk and talk, but it may also be true that were there to be better resources at home, he would have learnt to walk a long time ago.

Child left in a cot – Tiahuanacu (full mural 4.2.6)



8. Solutions suggested by participants

The existing situation for many disabled people is characterised by extreme poverty, isolation and rejection. Whilst there are several organisations that claim to work with disabled people, apart from associations of disabled people, there seem to be few who are doing anything to address the priorities of disabled people. Instead, as numerous disabled people put it, there are many that “are taking advantage of us.” The solutions proposed by disabled participants in this study are many and varied.

8.1 Self-Defence

There was general agreement amongst a group of teenagers in an institution in Sucre that, “you can’t change discrimination,” and that the only way to defend themselves against it, is to become ‘stronger’, so that they are not bothered by it. One person even said that they bring on the discrimination themselves by being weak. They also suggested that to solve this problem they need to break the cycle that, “the more we are discriminated against, the more we hide ourselves”. Several members of the group said it was not possible to change other people’s attitudes, only their own reactions.

Several people reported that once they learnt to defend themselves, things improved. Similarly the priority of a large group of parents of disabled children in Tupiza was that their children learn to defend themselves.

8.2 Separate institutions

The notion of needing separate institutions for disabled people was much more common among non-disabled interviewees and parents of disabled children than among disabled people themselves. Parents responded to the belief that it was unrealistic to tackle discrimination by saying the only solution is to have separate lives in separate institutions. A group of parents of disabled children in Tupiza said that in an ordinary school their children get bullied by other children and ignored by the teacher. The disabled children then get angry at not being understood and not getting the attention they need. These parents thought the only solution is a separate school. Similarly, the parents of a deafblind child said that if their child is not catered for in existing institutions then there should be a special centre. This is not just an isolationist strategy. One parent said, “a centre is needed where deafblind people can come together and show non-disabled people that we can do something.”

Other parents disagreed that separate institutions would help the situation, suggesting the solution is to educate non-disabled children and parents to accept disabled people (see section 2.4.1). As one parent put it, “if only all schools would open their doors to us.”

8.3 Education and training opportunities

Many disabled people described education and training opportunities as one of the main ways to solve current problems. Deaf people spoke of the urgent need to get more deaf teachers in schools to teach in Sign Language so that

education could be more useful to deaf children. A disabled person talked of his wish to become a teacher, he talked of the new strength and way of seeing things he had gained through becoming disabled: "With this experience I believe I can give the maximum to society, for this reason I wish that we would be given an opportunity." Parents of disabled children talked of wanting teacher training in order to teach their own and other disabled children. They stressed that they would do the work as a vocation whereas currently there is high staff turnover as non-disabled teachers do it for their careers and they can get better pay in other schools.

In rural areas deaf people or their families talked of the need for the opportunity to learn Sign Language. Blind people in rural areas also stressed the importance of somewhere to learn Braille. A parent of a deafblind child went so far as to say, "the only thing we need is training – for parents as well as for disabled people."

Non-disabled people also need education and training on disability issues. The medical professionals encountered in this research had not had any training regarding the needs and rights of disabled people as part of their general education. The first contact they had had with the subject was the course run by a non-disabled trainer from the NGO Rehabilitacion Integrada en la Comunidad (RIC). Instead of this situation, as one person put it disability issues should be, "part of the curriculum, whatever type of course should talk about disabled people." The courses should be run by disabled people for maximum impact, to counter the high unemployment among disabled people and in order to teach from personal experience.

8.4 Skills and experiences

Although many disabled people did talk of the need for training in skills for employment, many also pointed out that it was not for lack of training that there was such high unemployment among disabled people. It is commonplace for disabled people to be highly skilled professionals, who became disabled after gaining their skills and work experience, but are then unable to find employment due to discrimination. There are also the skills and experiences acquired as a direct result of being disabled, as one person put it: "Sometimes people only see with their eyes, but I have learned to see with my heart. Because I have suffered, I know what pain is." Or as a disabled young person put it, the skills and strength acquired from being disabled, "we can teach to other people." These experiences could be very useful in many areas of work, not least in NGOs that claim to work with marginalised people, but there need to be ways of pushing for recognition and employment opportunities.

8.5 Determination / need to organise

One disabled person, who has his own business, talked of his determination; of the support he had got from other disabled people and of how organisations of disabled people can help to overcome the obstacles faced.

The need to organise effectively was stressed, as one wheelchair user in a rural area said,

“Sometimes our suffering is too much. We are not taken into account in any way. We are capable of claiming our rights; I am capable of getting to La Paz, pushing myself in my wheelchair. If it concerned an organisation it wouldn’t matter how long it took, I would push myself up to a week with one hand to get there, but I would assert the right that I have as a disabled person.”

The need for effective organisations was seen as the way to solve many problems. The geese in the Santa Cruz mural (4.2.5) symbolise the importance of organisation.

“In Bolivia there must be lots of disabled people with different impairments, therefore I think of a big organisation where we would debate different problems, mine and other peoples, my brother’s - what are our needs - come to a conclusion and make that demand.”

Many people, particularly in more urban areas, suggested that with strong organisations of disabled people, it would be easier to tackle discrimination and to become a force that others cannot ignore. It is certainly clear that in places where there are strong organisations, the needs of disabled people are taken more seriously.

8.6 Support to associations of disabled people

The need to build associations of disabled people capable of representing members, supporting their needs and withstanding the pressure of misrepresentation by NGOs and others was seen as an area where support could be used from other countries. At present, few organisations have any funding at all, so they struggle even to have regular meetings, let alone to meet wider objectives. Some people suggested it would be useful to be able to exchange ideas and experiences with disabled people in other parts of the world. The idea would be to “to share the successes that have been made.”

One of the biggest problems for associations of disabled people is lack of resources. Disabled people talked of the difficulties members face in getting to meetings, of finding a place to meet and of accessing information. In poorer areas, people referred to the need to provide some form of incentive for those in the most isolated areas to attend meetings. If people are struggling to find food, clothing and shelter, then some say that spending energy and resources on going to a meeting is hard to justify, unless there are immediate benefits. However, several disabled people involved in this study showed huge determination in overcoming barriers to get to meetings. It was suggested that associations need funding to pay for their own transport and for some basic provisions at the meetings. It would be useful for associations of disabled people to get support in writing fundraising proposals. This support should come from a Bolivian disabled person, with direct experience of the issues that need to be addressed.

The movement is currently weak because it is split between blind people and other disabled people and between Codepedis and the federations of disabled people in each department. If associations had funding, then there would be less envy towards organisations such as Codepedis, Conalpedis and NGOs.

8.7 Use of media

The power of the media to spread messages relevant to disability was described, “through the TV I have seen organisations in other provinces...I think I saw in the anniversary of El Alto that they were organised there. But I don’t know where organisations come from, I am completely uninformed about this.”

Several people mentioned the possibility of using the media to inform each other and to bring disabled people together: “we must be quite a number of disabled people and we could meet, one way would be through means of communication, Channel 7 is what we watch most.” The Federation of disabled people in Patacamaya described how the group was set up by inviting disabled people over the radio to come to a meeting.

Television should make routine use of subtitles and Sign Language. Otherwise deaf people are excluded from both radio and TV communications.

8.8 Ways to change attitudes

The media can also be used as a tool to inform and change the attitudes of others. For this, disabled people would have to run their own radio or TV programme.

Disabled people talked of the urgency of changing non-disabled people’s attitudes so that:

- “We should not be seen as weird people”
- “If only they would not look at us as if we were something never seen before, like another race, if only they would accept us.”
- “When someone sees a disabled person they should help, not because they feel sorry for that person, but because they want to.”

Or as parents of deafblind people put it:

- “They should realise they are people.”
- “What he needs is for society to accept him.”
- “If society were to accept him, life would be much easier.”

Awareness-raising work can be done by all disabled people and needs to address attitudes of all around them. Some disabled people also talked of the need to change the attitudes of other disabled people, so that they think of themselves as able to do things. One disabled woman stressed the need to stop the self-pity among disabled people.

8.9 Campaigns

Attitudes need to be changed through campaigns, “I would like to work on an awareness raising campaign.” Local authorities or NGOs could fund these, as

long as disabled people lead them. Many times, authorities say the reason they cannot improve the situation for disabled people is for lack of resources. But as one disabled person put it, “the excuse is always lack of money, but doing an awareness raising campaign doesn’t need much money.”

Suggestions for the key messages of such campaigns were:

- “They should value us. We don’t need pity or them to say what a shame. We don’t want to be a burden, we want them to give us an opportunity.”
- “They should take us into account”.
- “We are part of society, we are Bolivians, we are human beings”.
- “Society should know that we exist and that we are going to work”.

These messages are very different from those being promoted in the awareness raising campaigns being run by the Ministry of Education and the NGO, Fe y Alegria.

Some disabled people talked of the need to make blockades, demonstrations: “we will make our presence known in the square”. “The demands need to be taken to government and to the Constitutional Assembly.”

8.10 Pensions, Food, Shelter, Clothing

Particularly in rural areas, disabled people suggested that a lot of their most essential needs could be solved by donations of clothing and food, access to housing and a pension or source of income. It was suggested that the old age pension should be given to disabled people at a younger age. Many disabled people will not live until old age. With even a little regular income, people could buy some basic necessities.

However, some disabled people disapproved of these suggestions saying this approach is ‘welfarist’ and that what disabled people really need is access to opportunities. The pension that blind people receive is certainly not without problems. Not only does it divide the disability movement, but one blind woman talked of how it leads to resentment, “the neighbours do not think we are important”. They say life is easier for blind people as they have a pension so they do not deserve any more help.

8.11 Transport

Some disabled people are against the idea of reduced transport fares, suggesting the reason it is hard for blind people to get a bus to stop is that the driver knows they do not have to pay, so there is no incentive to pick them up. On the other hand, others think of it as at least part of the solution, “transport should always be free for those at the margin of society”.

Many disabled people who do not get reduced cost fares also complain that drivers do not stop. One person suggested that the system requires drivers to pick up as many passengers as possible in a day in order to make a living, “bus drivers are ruled by the clock. They don’t want to waste time”. It needs to

be easier for the drivers to make a living, so that there is not such time pressure.

Some people stressed the need to get special vehicles for associations of disabled people. At present, transport difficulties mean that those with mobility impairments, or those who live in the more remote areas, cannot come to meetings, “we need a vehicle to pick people up”.

8.12 Employment

The alternative to benefits, whether in terms of low cost fares, pension, or food and clothing is that disabled people should have the opportunity to work and earn a living income. This is a major issue and solutions deserve more detailed consideration.

To achieve this, as one person put it, “the state needs to offer support”, private companies are unlikely to provide employment unless they are forced to do so, as their aim is profit not inclusion.

- “If there isn’t pressure, then there isn’t work. We won’t get anything without pressure. We have sent letters to many companies but there was no answer”.
- “We think if we had a centre, with a carpentry workshop, dining room, bakery, cobblers, then we would have a small company for disabled people... The government or an NGO would have to provide support at the beginning but we would show that disabled people are capable of making a living”.

If there is so little prospect of employment, people need training, support, start-up capital and tools in order to set up their own businesses. As a wheelchair user in Sucre put it:

“I see many disabled people in the street begging. From what I see these are normal people. Maybe in an accident they lost a leg, I don’t know, but someone should provide some training because I think these people could excel...”

“The other day I spoke to a mate, I invited him to the workshop. I told him, come and learn so that you won’t have to beg anymore and you’ll be able to work. You can train yourself. He answered that he couldn’t do anything; he had lost a leg. From that moment on, according to him, he couldn’t do anything. He couldn’t do what he used to do but manually he could do lots of things. Someone needs to drive these people.”

In Patacamaya, the association of disabled people is trying to set up a centre in which disabled people can make handicrafts to sell. The organiser of this explains, “we don’t have places to work. At least with handicrafts we can do something”. He was asked if disabled people should only have the option of handicrafts. To which he replied “We can take advantage of all the options available, but at least with handicrafts we can do something for our families.”

A few organisations say that they tried to employ disabled people but that either none applied or they could not find any with suitable qualifications. Whether or not this is an excuse, it is the case that many disabled people have not had the opportunity for education, training and previous work experience to compete with non-disabled people. As one participant put it,

“They should give support so that these people can get training and move forward, because for a disabled person it isn’t easy. They want to do things but they don’t have money to start. For example there are people who want to work in business but who don’t have capital...”

In the current situation it may be difficult for disabled people to compete with non-disabled people, therefore several people said there needs to be pressure on employers that do not employ at least 4% disabled people:

“There should be a law penalising companies that do not employ 4% disabled people... also NGOs should do the same.”

Some disabled people said that it should be recognised that some people will need assistance, as they are not able to work. These people should not be further marginalised by an exclusive focus on employment: “some people can’t work”. Similarly, the director of an NGO working with disabled people talked of the need for disabled people to get education and training, but acknowledged that some disabled people will, in reality, never be able to compete on the labour market. According to her, there will always be the need for centres for disabled people. These should not be like ghettos, but an integrated part of society. She went on to say that poor people could not be expected to look after their disabled relatives without help. Some disabled people need 24 hour a day attention, poor families cannot be expected to provide this unsupported.

The director of Aprecia in Sucre spoke of the need for NGOs to fund workshops where blind people can work - for example giving massage or physiotherapy. She reported knowing one blind person who is fully trained as a physiotherapist but cannot find work. Her concern would be more credible if her own organisation were to employ at least one disabled person.

Many people talked of the need to push NGOs to employ disabled people on a greater scale:

- “We are struggling to conquer this centre, this centre was created for us, not for non-disabled people, yet non-disabled people work here.”
- “The time has come for disabled people to administer these centres ourselves. We should be directly responsible because we are the only ones that can represent disabled people”.

Many NGOs, while claiming to work on disability issues, rarely employ disabled people. If these NGOs are receiving funds in order to work with disabled people, then they should be working on the priorities expressed by disabled people.

8.13 Opportunities for adults

At present, many more NGOs work with disabled children than with adults. This needs to change. Disabled adults talked of wanting somewhere to go, and parents of disabled children talked of the need for themselves to have lessons in relevant skills such as Braille, or Sign Language.

8.14 Control over the work of NGOs

After heavily criticising the work of NGOs, a government civil servant stressed that:

“Control over NGOs is important, not just to know how much money they control, but also to know what they do. If you know what they do, then the state can develop networks. If I know that you work on physical disability and there are 10 other NGOs working on this I can contact them and learn from your experiences. We can make a network that improves the service”.

However he also said that this was unlikely to happen,

“Just imagine what it would lead to, they would say that it is an interventionist authoritarian government...it wouldn't be good to generate other sources of conflict right now with NGOs...NGOs control a lot of money...”

So the government is unlikely to bring about any legislation to control NGOs at present. Similarly, disabled people were very free with their criticisms of NGOs in focus groups, and more so in private conversations, but when it came to expressing those views in the public mural-opening ceremonies, there was great reluctance to speak. People know that it is NGOs that control the resources. Whilst there might be great anger towards their work, nobody wants to risk them leaving and taking the resources with them.

The solution to this must be to build up the strength of associations of disabled people in order to withstand pressure from NGOs. This is not so easy to do as the reason for the fragility of many associations is their dependence on resources from others.

8.15 Revision and implementation of the law

The director of one organisation that works with disabled people said that an unfortunate aspect of the Disability Law is that it has become illegal to make a disabled person redundant. This organisation does not therefore employ disabled people unless there is absolutely secure long term funding. This may be an excuse, but it may also be an aspect of the Law that is counter-productive and needs revising. As one disability leader put it, “I think supreme decree 27477 has two faces: 1. Promotes employment and opens doors and 2. Generates rejection and closes doors”.

Members of the *Confederación Boliviana de la Persona con Discapacidad*, (Cobopdi) talked of the need to revise the Law. In order to do so, it would be useful to run consultations and to exchange ideas with disabled people in

other countries with similar socio-economic situations where there is good rights-based legislation. This is an area where NGOs could usefully support disabled people from the region to come together.

Information about the existing Law also needs to be disseminated. Few non-disabled people appeared to be aware of the Law's existence. A policeman even remarked that a priority for disabled people is that "they need a law".

Disabled people reported numerous examples of their legal rights under this law being ignored. People complained at being made to queue when legally they can go straight to the front. This is more of a problem for some disabled people than others. Deafblind people find it particularly difficult to stand for long periods without doing anything. A disabled woman complained that when she goes to the bank, she goes to the front of the queue but gets a lot of abuse for it. Many people do not know about the Law: "It says in the law that we do not have to queue. It is because of this that we have proposed running a media campaign to raise awareness of the law".

The association of disabled people in Tupiza talked of the need to have a campaign to teach people about the Law. They talked of needing the help of the media and of anyone that would work with them on this campaign. Similarly, Ramiro Delgado from the Ministerio de Gobierno said: "few people know about the Law, few people know about the issue. We need to work to let people know about disability rights".

8.16 Sign Language and Braille

Outside of the biggest towns, few blind people have the opportunity to learn Braille and few deaf people learn Sign Language.

For this reason, deaf people talked of the need to get Sign Language recognised as an official language in the constitution. Blind people talked of the need for wider opportunities for people to learn Braille and for government institutions at the very least to produce material in Braille. The current situation is that, for example, the government's *Plan Nacional de Desarrollo* was given to the Institute of Blind People several months after it had first been published. Blind people were then responsible for putting it into Braille themselves. It was proposed that the government should have a Braille machine and pay to get documents put into Braille on a routine basis.

8.17 Census

Several, particularly non-disabled, participants talked of the need for a census. One person in the focus group of non-disabled people said, "first we need to see how many disabled people there are". The figure that is currently most widely used is the global estimate of 10% from the World Health Organisation. As a civil servant perceived the situation,

"we talk of 10%, but how many are women, how many are boys, how many work, what sort of disability do they have, how many are children, how many adolescents, how many live in extreme poverty. We don't

have information on these things...when you have limited resources you need to prioritise”.

From the researcher’s perspective it would seem more productive, exactly because there are limited resources, to prioritise tackling discrimination in its various forms rather than counting people.

There have been attempts to count disabled people already. In Tupiza the Department of Education conducted a local disability census. According to the Director of Education, “we had problems counting disabled people because many parents hide them away”. A church representative explained, “They are ashamed and therefore say that there are no disabled people, but actually hide them”. The census found only 17 disabled children in the town, which is fewer than participated in this research.

The interviewee at the department of education in Sucre, who believed that it was unnecessary to improve physical access in schools, followed this by saying the problem is, “they don’t know how many disabled children there are”. Similarly the department of social development in Sucre talked of the need for a “clear diagnosis of how many disabled people there are”.

In the seminar to promote the *Plan Nacional de Igualdad y Equiparación de Oportunidades*, it was said that, if there had been accurate figures for numbers of disabled people, then there could have been a grant for disabled children similar to the grant for schoolchildren ‘*Juancito Pinto*’. But this grant was only for children in school, it did not rely on any statistics. The initial exclusion of children in ‘*educación especial*’, was not for lack of statistics but for lack of consideration.

See section 9 for further discussion of this issue.

8.18 Register

Another major focus of official bodies working on disability issues in La Paz is to register disabled people. At the time of doing the research, there were plans for a pilot project with funding from the Japanese aid agency Jica and representatives from the Ministry of Health and from Conalpedis. The plan was for disabled people to be assessed by a team of three professionals: a doctor, a psychiatrist and a social worker. This team would allocate each individual a disability score. Those who earned enough points would be classified as disabled.

At the time of writing, the future of this project looked uncertain, due to the conflict between the main organisations involved. The priorities expressed by disabled respondents in this research in any case make the rationale for a register extremely questionable, as will be explored in the next section.

9. Researcher's Recommendations

The following recommendations are not necessarily shared by all participants nor by the commissioning organisations. There is need for fundamental systemic change, but there are also many immediate practical steps that can be taken towards improving the situation.

9.1 Disability issues cannot be tackled in isolation. The systemic discrimination that currently exists must be addressed.

It is not chance that disabled people are excluded. This exclusion is a necessary component of a system that values people primarily as producers and consumers. At present, those who produce less quickly or efficiently are inevitably less valued. Fundamental changes to the status quo and the global socio-economic system are needed. The exclusion of disabled people cannot therefore be tackled in isolation:

- It is appalling when a bus driver refuses to pick up a disabled person. But; if that person would take longer than other customers to get on board; if that person is also exempt from fares (see section 2.7); if the driver's pay depends on how many trips are made; if there is no state payment for taking disabled people; if the driver is struggling to earn enough to pay for basic needs, then it is insufficient to simply blame the individual driver.
- It is inexcusable when mine owners discard disabled employees 'like an old machine' (see section 2.3.6). But who is ultimately to blame? Bolivian mine owners may exploit the situation but do not control the price of minerals. The wider blame must go to an international system that demands cheap minerals, where labour is seen only as a production cost to be cut as low as possible. In many of the mining parts of Bolivia, the soil is parched and contaminated with heavy metals, making it virtually impossible to make a decent living from farming. Miners themselves have little alternative but to accept what is offered.
- It is inhumane when communities migrate, leaving disabled people behind (see section 7). But if mobility aids are unavailable and disabled people cannot move with the rest of the community; if the soil is contaminated and the water has dried up, who is to blame? Community members are not responsible for the system that values cheap minerals for the international market above local food production, exploiting the land until the minerals have gone, and the land is unusable.
- If families hide their disabled relatives away (see section 3.3), rather than face the discrimination and shame associated with having a disabled person in the family, it is not sufficient to blame the family. The

difficulties that these families face must be addressed - rather than criticising those who are already struggling.

These issues are all inter-related. The need to change to a system which values people more highly than profits is recognized in the *Plan Nacional de Igualdad y Equiparación de Oportunidades* (PNIEO) as well as in the *Plan Nacional de Desarrollo*. Indeed, Bolivia is currently better placed to change the system to one more favourable to disabled people than the vast majority of countries. There is debate around how to build a more just and equal socio-economic system. Challenging the distribution of power and resources for indigenous people bears many parallels to the needs of disabled people. However, disabled people themselves are still not widely seen as the protagonists of change. Disabled people's organisations are mentioned only very low down the list of suggested executors of the PNIEO. Furthermore, the social movements that are so fundamental to the changes happening in Bolivia rarely seem to pay attention to the needs of disabled people. This is a major omission, especially as disabled people are among those with most experience of the destructiveness of the current system.

9.2 All those involved in working for disability equality should beware of distractions from tackling systemic discrimination.

There are many associations and federations of disabled people working hard to change the current injustices. If this work were supported and linked with the wider struggle for change currently taking place in Bolivia and internationally, then real success would not seem so far away. But the increasing focus on disability issues among governmental and non-governmental organisations in Bolivia is largely focussed on projects that do nothing to tackle the systemic discrimination that currently exists. Indeed, many of these projects serve to reinforce the status quo. The nature of these distractions needs to be exposed and attention focused on supporting those genuinely working for justice and equality.

Inevitably, when talking about fundamental change, there is resistance from some of those who currently gain most from the present system. Others may have the best intentions but be unable to comprehend the sort of changes that are called for. Often, those who first called for change are sucked into the whitewash that these distractions cause. There are numerous examples of such distractions:

A census

A census of disabled people (see section 8.17) would use up large amounts of time, attention and funding, but it is hard to see how it could reduce the problems described by participants of this research.

As the study in Tupiza showed, a census would be unlikely to produce accurate figures. People will not admit to having a disabled person in the house, unless the benefit is perceived to outweigh the shame and discrimination in doing so.

The representatives from the Department for Education claimed that knowing exact numbers of disabled people would help people realise they are not alone. But this would be a stronger argument for supporting organisations of disabled people. As was shown in Patacamaya (section 5.1), once there is an organisation, suddenly many disabled people appear and get solidarity from each other.

In the course of this research, it was never clear how policies would change if the international figure of 10% were found to be slightly higher or lower in Bolivia. Statistics would make no difference to the injustice faced. Indeed calls for a census seem to be a distraction from making the changes required.

A register

A register of disabled people (also as described in section 8) would be another distraction, but perhaps more dangerous for a number of reasons:

- Each person would be assessed and graded by professionals. Disabled participants in this research complained at how difficult it is to get others to listen and accept their expertise in what they live 24 hours day. A register assessed by outside professionals would serve to belittle the experiences of disabled people themselves even further.
- A register would be potentially divisive of the movement. One of the intended outcomes of the register is to expose those that are not really disabled. It was said that some people are posing as disabled people in order to get the advantages. The nature of these supposed benefits was never clear. Of course, some people have a more difficult time than others, but this is not necessarily related to the severity of their impairment. It would be far more constructive to focus on the cause of the problems than on ranking who has the hardest time.
- Unless discrimination is seriously addressed and the movement strengthened, then a register could actually make disabled people more vulnerable. It is not so long since oppressive governments would have been grateful for lists of disabled people to target their eugenics.

A register, like a census, could be an easy distraction for those in power - to be seen to be doing something without actually needing to change anything. This is not to say that this is intentional. It may be that people do want to change the injustice that disabled people face, but cannot actually conceive how things could be different. It is much less threatening to the *status quo* to register disabled people (particularly if the assessment of disability is directed by those currently in powerful positions) than to start addressing, for example, equal opportunities to work, education, health care or architectural access issues.

NGO rhetoric

Some NGOs have changed their rhetoric and now officially include disabled people in their priorities. But unless they also change the nature of their work, this is more likely to create a few acquiescent supporters among the individual

disabled beneficiaries than make any contribution towards changing the causes of discrimination and inequality. NGOs seem to find it easier to provide support to a small project **for** disabled people than to contemplate employing disabled people on an equal basis, or handing over power and control to organisations **of** disabled people (see particularly sections 2.3.4-5 and 6.3.3).

The commissioning of this research could be seen as an attempt to start to base work on the priorities expressed by disabled people. But after the research started, International Service actually contracted several more development workers to support organisations **for** disabled people, which this research specifically recommends not supporting. Furthermore their attempts to edit out criticisms expressed in this report does call into question the motivation for commissioning the work.

9.3 NGOs should make it clear where their basic allegiances lie - with their funders in rich countries, or with marginalised and oppressed people.

Criticism of NGOs and particularly international NGOs was pervasive among participants of this research (see quotes in section 6.3.3). From the researcher's perspective, it cannot be said that any NGO that participated in this research showed evidence of any concerted plan to change the status quo or the unequal power relations regarding disability or poverty. One high-ranking member of staff of a large international NGO described the structural causes of poverty, and said, "We cannot change the causes." However, their publicity does not make this clear to donors. Meanwhile, staff of these NGOs could be described as benefiting nicely from the existing situation. They would be exceedingly unlikely to afford such big houses or to employ servants if they worked in similar organisations in the UK.

There are clearly huge power differences between International NGOs and their supposed 'partner' organisations. A group of disabled people went to several international NGOs asking for financial support to lobby members of the *Asamblea Constituyente* to ensure that disability is well covered in the new Constitution. They were told funding such things is difficult as it is not sustainable: Evo Morales may not stay in power for long and the Constitution may not be rewritten. This may be true, but rejecting work on this basis is not supporting local people in their priorities. The NGO need for objectives to be Specific, Measurable, Achievable, Realistic and Timebound (SMART) provides easily identifiable results that give funders and staff a sense of achievement. But fundamental systemic change may not be achievable in the short term, nor provide easily tangible results. In the longer term it may be the only way to get real change.

The strap line of International Service is, 'Start with what people know, build with what people have'. There appears to be no question WHY people in Bolivia do not have more. In a practical sense, it would seem that the best thing that could be done for the Bolivian economy is to help the state take control of its natural resources. To do this in a meaningful way would require

investment in training of personnel and acquiring the equipment. However, this is not on the agenda of any international development agency that took part in this research. Instead, projects helping other NGOs that work for disabled people or street children or irrigation schemes abound. These projects may help some people, they may lead to donations from wealthy countries, but they do not address the issue of why Bolivia is poor in the first place.

There is an urgent need to expose the nature of the work of the international development sector. NGOs came in for a lot of criticism in this research, but NGOs do not work in a vacuum; their funding is often dependent on bilateral or multilateral organisations. These bigger organisations were never mentioned in this research but are implicated in many of the criticisms of the NGOs they fund. One local government representative, working to include disabled people in their consultations, complained that in order to get money from USAID they have to do “100 more turns to get funding from USAID for disabled people than for education. It is very difficult to get money for disabled people”.

In the same way that disabled people and the Bolivian government cannot afford to alienate the NGO sector, NGOs themselves are beholden to their funders - whether bilateral or multilateral organisations or individual donors. A member of staff of a large international NGO described how they are not able to do anything contrary to the wishes of their major donors. Ultimately it is not the NGOs that hold the power so much as their funders. Members of the government also spoke of their anger at the work of NGOs, but their powerlessness to put a stop to it as the NGO sector control much needed resources. This could only be tackled by building alliances so that those who need resources are less fearful of challenging those with resources.

9.4 Those aiming to support disabled people, should...

a) ...recognise that disabled people must be the protagonists of any change.

Most fundamentally, disabled people’s priorities, expertise and leadership need to be valued. Nobody can claim more expertise in a disabled person’s life than that disabled person themselves. Until this is recognised, wider change will not be achieved. As one participant in this research put it, the most important message is that “Disabled people in Bolivia insist that they should be the protagonists of change to their own situation”.

b)...focus on the priorities as expressed by disabled people themselves, not by intermediaries.

The priorities of disabled people expressed in this research were based on tackling discrimination and gaining equal access to food, clothing, shelter, work, education, transport and health services. Many NGOs do not in fact provide services that disabled people want. One international NGO, for example, provides foreign, non-disabled, development workers to support organisations for disabled people. No disabled participants in this research described any need for this. Indeed, as described in section 2.3.4, one

disabled person described how much better it would be to employ local disabled people, but said, if providing non-disabled foreigners was all that was on offer, then it was “better than nothing”.

The work of such NGOs maintains the power and control in the hands of non-disabled foreign ‘experts’. It exacerbates the notion that local disabled people are not capable of running their own affairs and that others know better. It also increases conflict within the disability movement, as organisations **for** disabled people get stronger whilst organisations **of** disabled people fall further behind.

Many organisations taking part in this work base their work with disabled people on the priorities expressed by intermediaries, not by disabled people themselves. Yet, this research found a marked difference between the manner in which disabled people and non-disabled people describe disability. Disabled people in all focus groups talked of the need to tackle discrimination, and to get access to employment, education and medical services. Few non-disabled people, even those working in organisations that say they prioritise disability, focused on these issues. Instead, many talked of the priorities as being rehabilitation, prevention of impairments and teaching families not to hide their disabled relatives away. Perhaps the most shocking aspect of this is that even the organisations that say they work with disabled people rarely base their priorities on the needs stated by disabled people themselves. When asked where their priorities came from, answers were, almost without exception, the ideas of staff or funding bodies (see particularly section 6.3.3).

Disabled people, in virtually every focus group, described the discrimination they experience as a routine aspect of their daily lives, rarely with any element of shock or horror. In contrast, those non-disabled people who mentioned discrimination at all, frequently talked as if each example they came across were a new and surprising revelation that should be tackled separately. It is non-disabled people in NGOs that control the funds but none of the NGOs that took part in this research could be described as working to tackle the systemic discrimination that exists.

Any organisation aiming to support disability equality should start by making their own work accessible:

- Their offices should be made physically accessible;
- Written material should be produced in Braille;
- Sign Language interpreters should be routinely offered;
- Staff and those accessing the organisation’s services should be routinely asked what access needs they may have.

Some specific examples of areas where participants suggested that NGOs could provide useful support include:

- Many deaf people and their families mentioned the desperate need for Sign Language teachers, particularly in rural areas. There are many unemployed deaf people who know Sign Language and who could become teachers if given the opportunity.

- Similarly many blind people in rural areas complained of the lack of Braille teachers.
- Parents of deafblind people talked of wanting to become teachers in order to offer their children better opportunities. They would be motivated by personal experiences, so the current rapid staff turnover would be likely to reduce.
- Some disabled people suggested that the law should be revised. To do this would involve bringing disabled people together to discuss current experiences and suggestions for change. It would also be useful to get the support of disability activists in other countries who have been involved in drafting disability rights legislation in similar conditions. NGOs should support the exchange of disabled people within Bolivia and between countries with similar experiences.

c) ...start employing disabled people on an equal basis.

Not a single NGO or government organisation was found that employs more than one or two disabled people on an equal basis to other staff (see particularly sections 2.3.2 -2.3.5). Some do have occupational therapy or sheltered employment, but people are paid considerably less than the minimum wage for such work. There are many skills gained from dealing with disability that would be useful to any organisation wanting to tackle oppression. Many disabled people were well advanced in their careers prior to becoming disabled. Those NGOs that work with disabled children need to at least provide some adult role models. Unless this is done, there is little credibility in claiming to promote the capabilities of disabled people.

The issue is not simply one of including disabled people in the existing work of NGOs. An indigenous leader, at a meeting regarding the inclusion of indigenous people in the constitutional assembly, talked of how inclusion and exclusion are two sides of the same coin. Having an indigenous President does not mean the system is no longer racist. In the same way, including a few disabled people in the work of NGOs does not automatically validate the work. Indeed, as was described in section 6.3.3, certain NGOs have been accused of “clientelism”, gaining support of disabled people by providing a few benefits to a few disabled individuals.

d) ...offer direct funding to organisations of disabled people.

A few NGOs already offer some support to disabled people’s organisations (see section 6.2). Direct funding of organisations of disabled people would serve to strengthen the organisation’s ability to represent and defend their members effectively. This is not to say that all organisations of disabled people deserve funding irrespective of how they are run. But the fact that an organisation is not run democratically could be a sign of the need for support. It is not necessarily a reason not to fund it.

Of those NGOs that work specifically with disabled people, many more work with children than with adults. As a disabled leader put it, this is because children do not fight for their rights. It cannot be coincidence that so few organisations **of** disabled people receive funding. People who are organised

are harder to control. Only a very foolhardy person in need of resources would risk criticising those with resources to distribute.

Disabled people's organisations need funding for meeting places, office equipment, and transport to enable members to come to meetings. The President of the national confederation Cobopdi talked of the need to bring disabled people together regularly to discuss priorities and build a stronger movement. However, this is not something disabled people could currently fund unsupported. These would be useful contributions that NGOs could make that would contribute to putting more power in the hands of disabled people themselves.

Summary

Whilst these recommendations stem from the needs and demands of disabled people involved in the research, many disabled people who took part in this research spoke of tackling discrimination as an unrealistic ambition. People who have been marginalised all their lives, might dream and campaign for more fundamental change but actually accept anything as better than nothing. The truth is that many disabled people are so desperate for improvement to basic living conditions that if some form of income, or access to food, water, clothing or shelter is offered, they cannot afford to refuse

The harsh reality of the current situation cannot be denied or belittled, but the most important recommendation of this work is not to be distracted from tackling the systemic discrimination. Sticking plasters may stem the bleeding but they will not stop a person wielding a machete.

Annex: List of focus groups and interviews

Focus groups

Sucre:

Aprécia - Blind children at Escuela Daniel Sanchez Bustamente
Asociación de sordos
Escuela Taller de Integración – ETI, Sucre,
Hogar 25 de mayo – institution for abandoned people
People with physical impairments – focus group set up by Codepedis.
Psicopedagógico.
Non-disabled people – focus group set up by Codepedis.
Taller protegido – sheltered workshop for people with learning difficulties.

Tupiza:

Asilo de Ancianos – Old people's home.
Asociación de discapacitados de Tupiza
Asociación de novidentes - Tupiza
Discussions with deaf people and their representatives and people who have had industrial accidents - (attempt to do group, but people arrived individually with at least half an hour between them. So ended up being more of individual discussions)
Families - three mothers and their children with Downs syndrome
Families - approximately 40 people - mostly families with disabled members
Rural area - Visquachani (2 hours journey from Tupiza), with Cuban doctors.
Attempt to do focus group but ended up being a few individual discussions.
Rural area – Santa Rosa and neighbouring communities

Potosí - No group took place despite several days of Codepedis saying people would come.

Santa Cruz:

Several short meetings with Jaime Estivariz B (President of Cobopdi), and with Armando Escobar Lino (President of Federación Crucena de Personas con Discapacidad - Fecrupdi)
Asociación crucena integral de personas con discapacidad (ACIPDIS)
Creo - Asociación de padres de sordos ciegos
Asociación de sordos ciegos Santa Cruz
Asociación de sordos de Santa Cruz (Asocruz)
Codepedis directorate meeting August (inquire)
Christian Children's Fund meeting with mother and 14 year old disabled daughter
Focus group of Federación Crucena de Personas con Discapacidad – Fecrupdi.
Federation meetings August and November
Montero – small town about an hour from Santa Cruz. Disabled people's organisation, mix of impairments.

Interviews

Sucre:

Alcaldia – asesor general (asked for interview with alcalde)
Alcaldia – Jefe de asuntos etnicos, generos y generacionales
Aprecia – directora
ASUR - directora
Audiologico
Ayninakuna directora
Defensor del pueblo
Escuela taller de integracion (ETI), two interviews
Hogar santa rita. Directora
Hogar 25 de mayo
OEA observers for elecciones asamblea constituyente
Prefectura - Desarrollo social (asked for prefecto)
Seduca. Responsable Planificacion. Fortalecimiento de infraestructura.
(asked for director)
Taller protegido

Potosi:

Centro de Penitencia - Secretario, Medico, Psicologa
RIC training of medicos, enfermeros and trabajadores social in Sedes, Potosi

Tupiza:

Centro de salud – trabajadora social
Gerencia de la red de servicio de salud de tupiza
Director de educacion
Iglesia - Padre and person working to set up school for disabled people

Mining:

Inspector de trabajo
Minas – miners at Paycoya, San silvestre, Tolamayu, two disabled miners from Churroma
Comibol – responsable Tupiza.
Federacion regional de cooperativas de atocha Federacion sindical de mineros
Pan American Silver mine company admin office
Cominesa (tupiza) – mining company

Medicus mundi
Seram (NGO)

Alcaldesa municipal Lorena Bernal Cruz
Subprefecto Sr. Sixto Martinez

Santa Cruz:

Council - participatory workshop led by social development department - one for NGOs and one for disabled people (or organisations that work with

disabled people). The stated aim of this was to make participatory budgets. At the meeting of NGOs met:

Sedes, Deporte, Seduca, Servicio departamental de gestion social
Sedeges, Plan Internacional, World Concern, Ayuda en Accion,
Servicio holandes de desarrollo SNV, USAID, Fundacion Ascender,
Fundacion SEPA, Instituto Boliviano de la Soya, PROCESO, Maria
Stopes, Vision Mundial, Villa Alegre – Christian Children’s fund.

Codepedis – several short meeting with director and heard presentations at other events.

Directorio de Codepedis – inquirate

Santa Cruz - NGOs

Aprecia - Director

Centro de Paralisis Cerebral – anniversary celebrations

Fundacion sindrome de downes FUSINDO – trabajadora social

Hogar Teresa de los Andes - trabajadora social

Plan International con PNUD, UNICEF, ASDI meeting about including children in development plans.

Plan international – coordinador tecnico de salud

SEPA (NGO) - directora

Vision Mundial

Villa Alegre – Christian Children’s Fund

Montero – centro de educacion especial Santa Lucia - directora

Montero – unidad para pcd

La Paz

Vice Ministerio de coordinacion con los movimientos sociales. Ministerio de gobierno. Ramiro Delgado

Ministerio de Salud. Responsable de discapacidad.

Ministerio de Planificacion – Ana Maria Guzman

Ministerio de Educacion – Directora de Educacion Especial - Katy Arce

Ministerio de Justicia – Vice Ministerio de Generos – Responsable de discapacidad Berto Calderon.

Ministerio de Gobierno, Regimen Interior, Director de Regimen Penitenciario,
- Ramiro Llanos

San Pedro carcel

Confederación Sindical Única de Trabajadores Campesinos de Bolivia
(CSUTCB)

Ecosolidar

Fe y alegria

Plan international

Sense International

International Service

USAID

Banco mundial

Guaqui – Centro de Salud, Plan Internacional

Tiahuanacu – Defensor del Pueblo

'I don't have a problem, the problem is theirs'

This research was carried out in Bolivia in 2006. The intention was to include disabled men, women and children living in as wide a range of situations as possible. Disabled people were asked about their priorities, what they would like to change and how. The same people then put their ideas in the form of drawings that were combined into mural designs. These sometimes retained the style of the original drawing; other times, the idea. Groups worked together to help paint the murals in prominent places. Inauguration events were held at which local authorities, NGOs, media and the public came to listen to participants explain the messages of the murals.

This publication describes the processes that were gone through and the main messages that came out. The analysis is that of the authors not the commissioning organisations who have produced a separate report.

The Disability Press

The Disability Press aims to provide an alternative outlet or work in the field of disability studies. The Disability Press draws inspiration from the work of those countless disabled individuals and their allies who have, over the years, struggled to put this particular issue onto the political agenda. Its establishment is testimony to the growing recognition of 'disability' as an equal opportunities and human rights issue within the social sciences.

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