Disability and Poverty in Rural Guatemala: Conceptual, Cultural and Social Intersections

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Acknowledgements

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1. Executive summary

This qualitative report complements a broader national survey of disability in Guatemala conducted in 2016. It responds to the fact that qualitative research, in particular that listening to, prioritising and articulating the voices and perceptions of poor rural disabled people in the country remain scarce.

The objectives of this report are to: explore cultural, ideological, and social interpretations and responses to disability; provide insight into the disability and poverty relationship; and examine social, political, and economic dimensions operating within this relationship. To accommodate these, in-depth interviews were conducted with disabled people and family members in 4 rural areas (indigenous and non-indigenous) and thematic analysis was employed in the bid to find common themes and patterns in the data.

Findings highlight a scenario of deep conceptual complexity, marking out disability as a notion and experience that is fluid, heterogeneous and dynamic. This is accentuated by complex and heterogeneous traditional folk beliefs co-existing with a hegemonic Christian narrative. Overall, these influence how disabled people, families and communities understand and engage with disability over space and time. The report maps out diverse social responses and attitudes that are not always negative, that operate along a spectrum, are dynamic, and importantly do not suggest systematic stigmatisation of disabled people. In the absence of safety nets and assets, families and poor communities, for better or for worse, are the only source of survival for disabled people. Findings continuously point to the predominance of shared poverty in rural communities as the point of focus, and how disability is constructed, responded to and lived. Deprivation, no access to safety nets, constrained livelihoods, infrastructural barriers, profound isolation and low assets among others are common realities that entrap all the poor. They also pitch poor people in competition with each other in contexts best described as 'survival of the fittest'. Within these spaces, barriers tighten for disabled people and their families, in particular those in livelihoods and health care costs. Whole families are cast into the most extreme and chronic poverty positioning these as the poorest of the poor- 'disabled families'. Findings highlight how this situation is created and perpetuated by deep structural inequalities and a policy and service landscape marked by disinterest in the plight of the poor, profound gaps and barriers. Within these spaces, rights and international declarations and their impacts, including the United Nations Convention on the Rights of Persons with Disabilities (CRPD) remain limited.

The report rounds off with a number of tentative recommendations for research, policy and practice. These include:

- The need for more contextualised longitudinal research sensitive to cultural, personal and contextual diversity and heterogeneity and that looks at disability through a family perspective
- The need to adopt a twin-track and multi-sectoral approach
- A call for policies and programmes that are knowledgeable of and responsive to the needs of the poor at large. This includes the requirement for universal social protection
- Strengthening of families as opposed to focusing exclusively on the disabled person in isolation
- Strengthening of communities and building on existing positive dimensions
- Alertness to and addressing of governance issues
- Creation of effective alliances between rural and urban organisations and other stakeholders

2. Introduction

It is estimated that some 15% of the world's population, or rather some 1 billion people, are disabled people (WHO and World Bank, 2011). Around 80% of these people are said to be located in the global South and the majority of disabled people live in rural areas, often in conditions of intense and chronic poverty. Overall, these numbers are increasing on account of natural disasters, wars and conflict, forced migration, more chronic conditions accompanying longer lives, and poverty and inequality among other reasons.

The arguments as to why disability should have a clearly defined space within international development, and why it should be a key policy and practice concern for every government, have been reasonably consistent. Apart from the sheer numbers of disabled people, the frequent reference to a strong relationship between disability and poverty has perhaps been one of the most cited reasons. The argument is that disability and poverty are not only connected, but are bound in a seemingly locking relationship, one often depicted as a mutually reinforcing cycle (see Palmer, 2012). Poverty makes people vulnerable to impairment, and the presence of impairment in conditions of poverty is met by a host of personal, socio-economic, cultural/ideological, infrastructural and political barriers that contribute to the creation of and/or intensification of poverty. Despite the absence of disaggregated, reliable and comparable data, the World Report on Disability goes as far as to claim that 82% of disabled people in the global South live in conditions of poverty (WHO and World Bank, 2011). It also goes on to state that one in five of the poorest people in low income countries are disabled people (ibid, 2011)

Overall, the emphasis on the disability/poverty bind continues to be critical for international and national disability lobbyists, arguing that if disabled people are among the poorest of the poor, then disability must be mainstreamed and targeted in policy and practice, whether this includes poverty reduction, accessible health care, inclusive education and/or sustainable livelihoods. Evidence, whether in the shape of grey literature, news items and reports from the UN Committee of the Rights of Persons with Disabilities (UN, 2016) has and continues to emerge even in countries such as Guatemala to highlight the harsh barriers confronted by disabled people in the country, and why the need to act is one motivated by urgency.

Despite these positive shifts in discourse, signing and ratifying of the CRPD by many countries including Guatemala, and recently the inclusion of a disability component in the Sustainable Development Goals (SDGs), the reality though remains one of crisis. The following statement in a recent report by CBM, captures the situation:

> While the majority of the world's governments, international development organisations and civil society members working in international development activities are in agreement about the importance of including persons with disabilities in the process of development, the journey to get there continues to be seen as a challenge (2014: 10)

Disability continues to exist on the peripheries of development and national level policy, research and programs (Grech, 2015). Riddell (2010) for example estimated a few years ago that less than 5% of overseas development assistance (ODA) is allocated to disability. Others document how mainstream development and national level programmes (e.g. education and employment) continue to bypass disabled people, often at substantial economic and social cost (see Banks and Polack, 2014). Even targeted programmes (including by non governmental organisations) such as those addressing the needs of children, women and ethnic minorities continue to be planned and implemented in non-inclusive ways in countries such as Guatemala (see Grech, 2015).

Reliable disability statistics may offer numerous advantages, including that of motivating policy makers to take action and to effectively plan, implement, monitor and evaluate policies. They can also support efforts by those lobbying for mainstreamed and targeted intervention. However, in practice there is very limited (if any) internationally-comparable data on the rate and distribution of impairment at a global level, while national-level data that does exist, is often of poor quality, unreliable, and/or out of date (especially that collected through surveys). The truth is that noone knows with precision how many disabled people there are, including in Guatemala. Disability (just like poverty) means different things to different people in different contexts and cultures, including within one country. Reliable and consistent data generation is hard and is an area that necessitates more work and in-depth discussion (see Eide, 2016 for an in-depth critical discussion on disability statistics).

Even more seriously, there remains a dearth of empirical work, in particular critical qualitative research on disability and its various dimensions in the global South (Grech, 2011, 2015). Research focused on rural areas, in particular, continues to be dramatically scarce, reflecting how these spaces are distant or forgotten- geographically and politically. Latin America, sub-regions such as Central America and countries such as Guatemala continue to be dramatically under-served by research. Many of the countries in the region have erroneously and conveniently been cast in the 'middle income' bracket by parties such as the UN, despite soaring rates of poverty and inequality. This means not only less funds for development programs and aid, but also for research. In Guatemala, there are very few publications on disability other than policy references and a small number of reports. Much of what exists is grey literature with a minor or no empirical component produced by the non-indigenous urban elite and their associates. Importantly, what defines this output is little or no actual contact with poor disabled people in rural areas or knowledge of their social, cultural, economic and ideological realities. The voices of disabled people outside the capital city, in particular those of indigenous people, remain worryingly absent and unheard. Disabled poor rural people are rarely in a position to speak for, represent and advocate for themselves. Power, including in the disability sector, is not only concentrated, it is marked by a profound urban bias.

Worryingly, disability is a thematic abandoned in research on other/more visible issues and populations amply addressed in the literature on Guatemala, including gender, poverty, livelihoods, conflict, race, and even health. Few (if at all) are the attempts at exploring at the very least the many intersectionalities e.g. the situation of disabled women or disabled migrants.

Despite the all too frequent references to disability and poverty, enormous gaps also persist in the exploration of this relationship and the dynamics operating within. Except for notable exceptions (see Grech, 2015), there is virtually no research in Guatemala. The experience of disability in various contexts and the disability/poverty relationship in the so-called *interior* (internal countryside) remain the product of hearsays, assumptions and inferences too often created and perpetuated by urban stakeholders. In turn, the rural narrative fades away, power is relegated to so-called urban 'experts', and poor disabled people are seldom afforded the space to speak about their own lives. Throughout this process, how disabled people and their families live, negotiate and survive disability remain a closed box, with serious consequences for policy, advocacy and services that remain decontextualised, often ill-informed and unresponsive.

3. Objectives

The main object of this study are the lives and narratives of disabled people in rural areas. The study aims to provide critical information on contextual, cultural and social landscapes in Guatemala and their interactions with disability and poverty. Through this, we hope to contribute knowledge on cultural framings and the disability/poverty relationship and to inform research, policy and practice.

The immediate objectives of this qualitative study are the following:

- explore in-depth cultural, social and ideological/religious dimensions and how these construct disability

- investigate some of the connections between disability, poverty, and cultural, ideological/religious constructions.

- examine some aspects of the social and political landscape in rural areas and how these impact disabled people and their families

- illustrate some dimensions of the policy and service scenario and how rights translate on the ground

4. Methodology

This study adopted a qualitative approach with loosely ethnographic leanings, in the bid to prioritise and articulate voices and perceptions of disabled people within their context. Fieldwork was conducted in 4 rural areas in 3 departments of Guatemala. Two of these areas are predominantly indigenous.

4.1 Methods

A purposive sample was drawn from a sampling frame provided by key gatekeepers. These included trusted DPOs and national organisations. The main methods of investigation included in-depth unstructured interviews conducted with 27 disabled adults (14 men and 13 women) residing in rural areas whose ages ranged from 18 to 67. Five participants had intellectual impairments, 3 had sensory impairments, and 19 identified as having physical impairments. All participants self-identified as 'disabled' (or a variant of this) and 'poor' or 'living in conditions of poverty'. Interviews were also conducted with 6 family members in an effort to triangulate and add detail. Interviews were largely held in participants' homes. A small number of interviews were held in a private room on the premises of the NGO acting as gatekeeper.

Most interviews were held directly in Spanish. In a small number of cases, a translator/cultural mediator was used with indigenous participants who do not speak Spanish. While these were not professionally trained translators, they had experience translating for organisational and other

personnel. They are also known to and trusted by participants. Interviews were recorded using a digital voice recorder and later transcribed verbatim.

4.2 Analysis

Thematic analysis (Braun and Clarke, 2006) was employed in the study in the bid to find common emerging patterns in the data using a process of coding, that is the generation of categories and sub-categories. All transcripts were manually coded and analysed. All details about the participant, location and other identifying aspects, and names of people have been changed in the findings below to protect identity.

4.3 Ethical procedures

All necessary ethical procedures were followed in this study. Participants were clearly explained the scope, approach and direction of the fieldwork and the study in an accessible way, and consent was provided by all participating. Aspects such as participant rights including the right to withdraw at any time without explanation were emphasised. Confidentiality and anonymity were assured and guaranteed to participants through measures including the coding of transcripts, the use of pseudonyms and safe keeping of data by the key researcher.

4.4 Limitations

Like all pieces of research, this study is not without its limitations and needs to be read with some points in mind:

- Time and resources were limited. This meant reduced ability for repeat interviews, and to follow up on key emerging issues.
- Secondly, this study is no way meant to generalise the disability experience, cultural conceptualisations or the disability and poverty relationship onto the rest of the country. It also does not claim to be the voice of disabled people and their families.
- Guatemala and its rural areas are hugely complex and diverse- socially, economically, culturally, racially and ethnically among others. Critical dimensions and in-depth understandings can hardly be captured in such a small short term study.
- The limited number of participants, types of impairments and locations, mean that many voices and perspectives are left out or inadequately represented. These include those of people with intellectual impairments, those who speak exclusively an indigenous language, those residing in urban areas, and people who do not consider themselves (relatively) poor among others.
- My own presence, identity and status- essentially a non-poor, non-disabled, white foreigner and outsider, impact not only how information is filtered, but also what people share, and how they share it.

5. Findings

The following sections map out the key emerging findings from the study. They are not organised in a progressive fashion, but as will become clear, they reflect an often interconnected landscape.

5.1 The complexity of disability in rural poverty

A range of literature on global disability has and continues to express concerns about the complexity and difficulties in defining disability across cultures, challenging in the process standardised and/or generalised definitions (see for example Whyte and Ingstad, 1995; Grech, 2015). Findings in this study support this, highlighting how:

- disability is complex, multidimensional and changing
- there is no one fixed definition of disability
- disability is not bound to fixed, established and static hegemonic models of disability (e.g. medical or social model of disability)

Participants in the study, more often than not, were not conversant with any formal definitions or models of disability, or even disability rights discourse, including that used by activists and other stakeholders in urban areas in the country. This included for example the resistance towards charity approaches (*asistencialismo).* They were also frequently not familiar with people-first terms such as 'person with a disability'. Instead, they used words such as 'ill person', 'sick person, or 'invalid' to refer to themselves. Disabled participants insisted they were cut off, lived in poverty and had little or no idea of what happened in the capital city.

Interviews are clear in suggesting that poverty and living through it is the main concern and priority for disabled people- everything else is superfluous. Furthermore, it is in relation to this poverty that disability materialises and comes to take meaning for disabled people:

> I don't know any of these definitions or these rights that you mention...I am just a person who is sick…what they talk about in the city, I have no idea what that is, they never come here...so yes a sick person is what I am...what fills my mind is poverty...if one day there isn't food for my children...and so what I do is cry and ask God to help me...this is what preoccupies me, poverty...because one wants to have with what to give the children, so that they do not go hungry or at least their clothes... (Juana)

When asked how they understood or defined disability, participants in the study offered multiple words or phrases for what most called their 'condition' and life as a disabled person within contexts of rural poverty. The following quotes are illustrative:

- 'Illness because here there isn't health care' (Elena)
- 'A tragedy in this poverty' (Manuel)
- 'Remaining paralyzed like this and not being able to work to earn your cents to be able to live' (Geovani)
- 'Pain and suffering without help because we have nothing' (Teresa)
- 'Invalidity...a damaged body because here one needs a good body' (David)
- 'A misfortune with no money...a life that is no longer like before, stolen from me, like I died...' (Fausto)
- 'Not being like others' (Roberto)
- 'Less than others because I cannot provide for my family and my children are going hungry' (Wilfido)
- 'What God wants and so is God's will, I accept it...' (Maria)

These experiences and views cover a range of social, economic and political dimensions, but it is possible, though, to see that there are some common aspects:

- First of all, most have a focus on the impairment and its impacts or limitations imposed on the body, what Thomas (2004) would call 'impairment effects'.
- Secondly, they are rather negative perceptions and even a tragic view of the lived disability experience.
- Thirdly, and most importantly, this tragic view of disability is bound to barriers confronted by disabled people in poverty spaces that are not equipped for or meant to host disabled people.

The third point above, suggests another two key issues:

- Understanding or starting to understand disability within context, implies first engaging with what it means to live in and survive rural poverty: this poverty not only surrounds disability. It a source of complex barriers that often become insurmountable for many disabled people.
- Within these spaces of deprivation and hardship, disabled people also come to meet a host of disability-specific barriers. Overall, disability impacts the resources available to fragile poor rural households.

As this indigenous participant succinctly put its, one needs to first start with an understanding of rural poverty and then work outwards to grasp what it means to be disabled within poverty spaces:

> ...look around you, there is no work, the houses have water and animals coming in, and we have no money and sometimes no food, our children go hungry, hospitals treat us like rubbish…and then comes this cursed illness, you have to spend money on doctors and you can't, and then you can't buy food, what can I tell you? Look around you, how do you expect someone like me to survive here? (Manuel)

Asked what constitutes rural poverty, participants provided a multidimensional picture of life in poverty that isn't simply about lack of money:

- Complex and hard rural livelihoods:
  - limited, fragmented and unsustainable livelihood activities in the informal sector
  - dependence on labour intensive work requiring physical strength
  - seasonality of agriculture, influencing labour opportunities, output and prices
  - hurdles in obtaining primary inputs for farming (e.g. fertilizer) impacting yield
  - scarcity of land for farming and/or to use as collateral for loans
  - presence of share-cropping arrangements and work in kind
- Vulnerability to environmental crises and disasters (e.g. drought and floods)
- Relative physical isolation from main thoroughfares: this affects access to goods and services (e.g. health care), costs (e.g. transportation) and prices (e.g. of productive inputs).
- Harsh physical infrastructure difficult to navigate, especially in rainy periods and that once again requires physical strength
- Absent or fragmented heath care services centralised in Guatemala city and department heads
- Local health centres in rural towns that are erratically open and often unequipped

- Very low levels of and inconsistent income, and low levels of or no savings: a day's labouring in agriculture may be as low as Q50[1]
- Food scarcity and periods of under-nutrition that become more regular with increasing dry spells
- Difficulties in covering the costs of the food basket
- Unsanitary and unsafe living and working conditions
- No formal safety nets: most labour is in the informal sector which means that workers are unregistered, do not pay tax and are hence not entitled to social security (IGSS)

These are only some of the aspects that characterise the hugely complex and dynamic rural landscape. Nevertheless, what the points above highlight, is a life of constant hardship, lack of assets, instability and insecurity, vulnerability and overall deep and chronic poverty. The following quote by a man living with spinal injury in a remote mountain village sums this up, highlighting how the prospect of illness and disability is a major fear for those in chronic poverty:

> Life here is a hell that we, poor people, live on our own...there is nothing or noone to help you, there is no work, no money, just suffering and hunger...it doesn't rain and the crop does not give...you get sick and you cannot get to a hospital…you can die here any day, so illness is the thing we the poor fear most…poverty goes on forever for you and your children (Guillermo)

5.2 Disability and Poverty

Within these contexts, as participants emphasised, the barriers imposed by poverty strengthen for disabled people, and become difficult, if not impossible to negotiate. Furthermore, a host of new barriers are enacted that are specific to disabled people. In the absence of safety nets, survival itself is often compromised, fuelling the notion of disability as a tragic event, or rather as one participant put it, 'a rupture in normality' *(Ruptura en la normalidad)*. Among those most impacted are people with serious and chronic impairments and those affecting mobility, people with visual impairments, and those in need of regular and emergency specialised health care.

Findings highlight how while disability does create a host of barriers that only disabled people have to deal with (e.g. specialised health care), the real reason for poverty tightening its grip on disabled people is that many of the activities that typify life in rural poverty and that are normally performed by the poor, can no longer be performed by disabled people, or only partially. The dirt tracks they navigate daily to get to farm or sell their produce become unmanageable for those with mobility impairments. Similarly, searching for and carrying water and firewood become difficult if not impossible. Disability then introduces a host of costs on vulnerable, fragile and unprepared households. The following participant maps out this process:

> We were always poor, we never had money but somehow we survived, work the fields, and go where there is work (migratory labour). This illness I have has ended all this, cannot even walk when it gets muddy. This illness is one of rich people, we have nothing left and the poverty we face now is like waiting for death...a death sentence (Teresa)

The barriers that come to confront disabled people and that contribute to dramatic impoverishment are extensive, interconnected and complex and cannot be addressed with the care and complexity

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1 1US$= 7.5 Quetzales (December 2016 estimate)

they require in this small report (see Grech, 2015 for more nuanced readings in the Guatemalan context). Below, I highlight two critical areas.

5.2.1 Stalled livelihoods

Poor people are on their own. Whether they eat or not, whether they live or perish, depends solely on their ability to labour and earn some money however little this may be. Families work together and pool money, and their objective is simple: covering the costs of the food basket. The need to grow some of their own food is critical in the bid to reduce the cash outlays to cover this basket. There is little if any money left over for anything else.

Disability and the limitations imposed on weakened bodies, and the absence of lighter work alternatives, meant that for most participants, the hard labouring activities they performed before, including seasonal migratory agricultural labour had to be terminated abruptly. Those with certain congenital impairments, never started labouring:

> When I was in good shape, I went to the fields and worked. I worked in agriculture, I had a good body before. Now that I cannot, I no longer go out, things have changed a lot because I can I cannot do what I did before...when one is good, one takes to the fields to cut the wood, to grow his crop, and brings it home…one goes to the mountain to look for animals...and catches fish so the family can eat...when I was good, I got work in other places and earned my living far from here. I would spend 15 days working there and made my cents...but now that I am no longer able to to do all this, I feel exhausted (David)

A number tried to continue labouring, but their input was often erratic, contingent on levels of pain, and more often than not had to stop because they risked injury and secondary impairments (e.g. on account of accidents) they could not afford to medicate.

Within such contexts, all poor people have a dramatic need to labour. This means that they are often pitched against each other. With an oversupply of able-bodied workers desperate to work, participants emphasised how priority is therefore given to strong non-disabled workers. This also includes disabled people's own family:

> There are too many poor people here, we all need work, all struggling...so who is going to even consider me? (Juana)

Livelihood activities are interrupted or weakened also by extraneous factors. At the time of the study, whole villages were preoccupied by the lack of rain. Speaking to families, many were in a state of despair, had lost the crop along with their investment (seed, fertilizer etc.), prices of bean and corn were already starting to escalate, and under-nutrition was an impending reality for many, especially for those in the dry corridor. Higher market prices and crop failure would have meant more money required to purchase the food basket. At the same time, opportunities for paid agricultural labouring were vanishing.

In poor rural areas, less strenuous work opportunities are also scarce. Work is largely undiversified, there are no paid jobs in the formal sector (other than the privileged and connected few), and poor people lack investment capital to start their own business. If or when they manage to start a small business, for example the small *tienda* (shop) selling basic foodstuffs, this meets a context of low disposable income and often extreme competition. Two participants recounted how they had tried to set up a small shop selling basic goods, but the competition was so rife, and spending power among

poor people was so low, that they soon went out of business. Indigenous participants who took to weaving as an emergency strategy underscored how the market is over-saturated, disposable income is severely constrained, and how middlemen severely constrain the profitability of these activities.

5.2.2 Costs and no money

Disability also constitutes an extraordinary strain on poor households, especially when it introduces new financial costs, known in literature as 'direct costs' (see Grech, 2015). The most urgent and impoverishing costs documented by participants were those incurred on obtaining health care and medication. This was once again the case for those with serious and chronic impairments. Overall, participants highlighted three major costs they confronted in seeking and securing health care:

- Transportation and lodging: For those in distant rural areas, travel costs are very expensive. They are also not always available or accessible, and indeed some disabled people are barred from using local public transport (e.g. *microbuses* (local minibuses) or charged higher prices. Barriers in local transportation mean that some are forced to rent a private vehicle to reach a medical facility, especially in times of emergency. Transportation costs have to cover those of the disabled person and the accompanying family member and a trip also involves costs of food alongside those of lodging because distance may mean an overnight stay.

- Consultation and medical intervention: Public hospitals have a long waiting time, materials are not always available or covered and need to be purchased, and alternatives may be limited to private clinics and hospitals at exorbitant prices. It is not unusual after the trials and tribulations of reaching a hospital, for people to simply go back home with referral papers and prescriptions in their hand, poorer and some in debt.

- Medication and medical supplies: one major cost for disabled people, especially those with chronic impairments is medication. With no price controls, the price of medication varies wildly in Guatemala, implying that apart from the cost of the medication, poor people also have to invest time and resources searching for cheaper options.

Overall, what pushes up these costs is that specialised health care services are often not decentralised, only available in Guatemala city or in department heads, many kilometres away from those in rural areas. The following quote from a participant with kidney failure documents the hurdles and costs involved in seeking health care in the capital city on regular basis:

> ...from here, the department head is an hour away, but there they do not have the necessary equipment for what I have, and from there it is 3 hours to the capita city...one gets ill here and then has to go all the way there. To go all the way there by bus, one spends Q200. One has to stay 2 or 3 days and you have to find lodging, pay a small flat where they don't charge much...and then come back. Sometimes I have to go hungry because I do not have enough money left. This is what it is tough here in   the village, because it is not like another illness, for example a cold, a cough... (Mario)

Catering for these costs is a major hurdle and preoccupation for disabled people and their families. Interviews documented in detail the extremes they went to to patch together the amounts required for some or other pain relief, with dire consequences. These included pleas for handouts from

family and neighbours and also informal loans at extremely high interest rates from moneylenders (sometimes up to 18%). The latter sometimes led to debt traps.

Confronted by loss or fragmentation in livelihoods activities (including those of family members), few or no savings, the urgent need to provide for immediate food costs and to eat, and the very high prices of medical services and medication, the option for most participants was either to cut down on health care or to stop it altogether:

> Everything was scarce, it wasn't enough for the medication, and if was enough to eat, it wasn't enough for medicine (Roberto)

> Doctor X told me 'you need an injection that costs Q1000- that isn't available here- I have to go and get it from the capital city'. I told him 'no doctor, I don't have money, I am poor'. I had gone because I had sold some corn because I had worked here abit, this is how I went to X (department head). By the end, I spent like Q1500 on what he gave me and the medication. And by then I did not want him to give me the injection. I say that it was lost money... I only went once, I didn't want to go again (David)

5.2.3 Disabled families: a life of extreme and chronic poverty

Interviews are replete with narratives highlighting how the lives of disabled people are marred by pain, extreme financial poverty (assets are effectively drained), low consumption (including of food), low productivity, insecurity, and even social isolation. Disabled people, it is safe to say are among the poorest of the poor. While few of the poor in practice 'move out' of poverty, for disabled people, this poverty effectively becomes an incarceration for them as well as their children, taking strong intergenerational dimensions. While most participants did not beg, many became dependent on handouts from family (including extended family) and communities of small amounts of money or food. Uncertainty and insecurity were constant and articulated preoccupations:

> My dream is to live a more peaceful life, to not be constantly worried because of so many things, above all because of the poverty and because of my disability. I would like to have a more peaceful life, to have my food, to have my cents to get by, to have money to go to a doctor or something and to control the illnesses that I have in my body and that my family too can have their food...this is why I would like a more peaceful life and not have to worry so much about the poverty and the disability I have, because it is horrible for me. Being sat in the wheelchair nearly all day, and now that I have spent some 20 days only lying down, all sluggish in bed. It is hard for me (Geovani)

Geovani, the participant above, died suddenly a month after this interview, having struggled for years to access the health care he needed.

For some, poverty, extreme pain, hunger and the pressure imposed on their poor families led to deep feelings of hopelessness and even guilt:

> There are moments where the worries make one become ill more quickly. One spends his time thinking 'what will I do tomorrow', 'what will I eat tomorrow?', 'will someone help me?', 'will my children eat?', and this is how it gets into your head...I can't sleep anymore (Estela)

The narratives are clear in suggesting that disability impacts not only the individual, but instead

impoverishes the whole family, positioning these as 'disabled families' (Grech, 2015). Evidence from this study highlights a range of responses by family members in their attempts to help the disabled person survive, but which in turn impact their own well-being and their own poverty:

- Shifts in labouring patterns: following the onset of impairment, reduced labour input from the disabled person and health care costs, family members are frequently pushed to work harder and longer hours to compensate for these costs. Extreme poverty sometimes even pushes women and children into exploitative work, interrupting in the process their education and exposing them to a host of abuses.
- Reduced consumption of food: family members too may be consuming less because financial resources are drained, especially in seeking health care for the disabled family member and on account of his/her lost labour input.
- Reduced access to health care: the dramatic expenses on the health care of the disabled person often leave no money for the health care of other family members. This opens up a space for illness and even impairment.
- Care-giving: just like housekeeping, this is a task disproportionately borne by women. Participants spoke about the immense strain on these women who saw their time eaten up, sometimes forced to leave paid labour and constraining their time to engage socially:

> You cannot leave her (disabled person) alone and you go to work, you can't. Your father or your mother have to stay. If both stay, who is going to maintain the family? And if they go to work and the disabled person stays, who is going to help her?...when there is disability, it affects the family a lot (Carolina)

From pooling of labour, handouts to cover some health care, feeding and caregiving, without family, disabled people it is clear, will not survive. Participants spoke about numerous fears, but the most pervasive one was that related to the loss of their family. In this respect, they also expressed the dire need for support for their family members:

> I know that my sister is ready to take care of me, and I too would like her to have some help, so that she can stay with me, because it is not so easy...because take for example if she wants to go to work, she cannot, because she cant leave me...this is why she too needs some help… It would be terrible, don't go there, without family and without sisters, without uncles or anything...who knows, I would even wish for death, because me alone...(Geovani)

5.3. Indigenous landscapes

Disability needs to be positioned and understood within the physical and economic but also cultural, ideological, social and even racial context (Soldatic and Grech, 2014). In Guatemala, indigenous communities and locations are fraught with too much complexity (including historical ones) to be captured here in a few pages. They, nevertheless, deserve to be mentioned within a country also known for its profound racial and ethnic divisions and continued racism. Indigenous populations continue to be among the poorest and most isolated people in Guatemala. When disability is brought into the equation, as participants suggested, disabled people sometimes confront the double bind of race and disability. They are effectively 'raced and dis/abled' (Annamma et al. 2013:5). As one indigenous participant put it:

> You are poor because you live here, because you have a body like mine, and on top of that because you are indigenous… the worst among those who are suffering (Ermelinda)

Indigenous participants stated that while many of the barriers imposed by poverty were intensified for indigenous communities (e.g. scarcer livelihoods opportunities, harsher infrastructure and remoteness), it was also through profound racism that poverty intensified. One common experience for disabled participants was that of facing medical facilities in urban areas where medical staff are predominantly *ladino* and speak exclusively Spanish. The absence of a cultural mediator and translator in these facilities meant that they often could barely explain themselves, and when they did, were unheard or treated without respect. On top of this, feelings of shyness and shame (*verguenza)* associated with these interactions alongside distrust of doctors and hospitals, fed into much discomfort to the point of not returning:

> I do not like those places (hospitals). They see us (indigenous) like we are from another world, they do not want to understand you. They do not look you in the eye, no respect, like rubbish. You understand nothing. Its all about money…they want your money and do not care what they do to you. They say 'you need operation', but I do not trust them, they will tell you that just to make money...I heard stories where they even operated for nothing. I prefer to not go (Ermelinda).

Policy makers and service providers as well as urban civil society too are distanced physically and even mentally from these areas and people. Indigenous people remain the subjects of hearsays and myths. This has serious implications as to the extent to which urban NGOs, including DPOs are knowledgeable of the realities of disabled indigenous people and the extent to which they can claim to represent them. I discuss this further below.

5.3.1 Cultural and ideological framings of disability

Guatemala is a complex context also when it comes to religious and ideological beliefs and their manifestations within communities. The colonial invasion meant not only physical violence and profound pillaging. It also meant an organised assault on the many Maya beliefs and their Gods, seen as products of the devil (see Lovell, 2005). Catholic beliefs framed the invasion as a mission of God, while mass evangelization became a means of social control. Historically, though, while many of the Maya beliefs and rituals were driven underground, they were all but eradicated. Instead, they fused and combined, creating hybrid beliefs, religious figures blending Maya and Christian beliefs, alongside complex rituals traversing spiritual and material worlds that survive till the day and are given much importance.

While efforts were expounded in the study at exploring in depth cultural and ideological beliefs about disability, evidence suggests not only that these are too heterogeneous and complex to be captured in such a small study. Importantly, they appear to be sparse, erratic and too incomplete to generalise that there are specific or well-defined beliefs about disability that are localised and/or that these are systematic and diffuse enough to state that there is a pattern. What emerges clearly is that there seems to be a sharp distinction with discourse propagated by organisations and lobbyists, especially those in Guatemala city. Over the course of the years, as well as in this study I have met many organisations who will easily state that in indigenous areas, disabled people are worse off, often subject to stigma, oppression and even persecution on account of strange traditional beliefs. Yet, when asked if they had personal knowledge of these or knew if they were factual, they stated that they didn't know. During the course of this study, I had informal conversations also with rural DPOs, who did mention the existence of certain beliefs, and who claimed to have heard them, in

particular the notion of disability as a result of sin. Yet, when asked to explain further, many claimed that they had only heard about these from secondary sources and did not know enough.

One key finding is that ideas about these beliefs and more broadly indigenous people by outsiders appear to be strongly bound to their continued Othering and generalisation. This is not surprising, when indigenous people continue to be unheard, rendered invisible, subjugated, spoken for and unpermitted to speak for and represent themselves. Notions of geographical distance and isolation and also history are often used by privileged outsiders to homogenise and contain them. In turn, they are regularly subjected to a series of xenophobic perceptions on a spectrum of negativity- that they are child-like, unlearning, ignorant, uneducated, violent, uncivilized to name but a few.

To be clear, findings do not suggest that beliefs around disability, in particular its perceived provenance do not exist or do not impact the perception and treatment of disabled people. They do in some instances, but these do not appear to be diffused or systematic enough. Instead, they seem to be intermittent hearsays as opposed to concrete beliefs; seem to have been more dominant in the past; and overall are not always taken too seriously by disabled people, contested by medical and also religious interpretations (see below). This quote brings these points all together:

> Here, people believe many things. I have heard something from my parents, or someone told them something...I don't know...but I don't believe them, like things from the old days, maybe they believed them before, but I have not heard them myself. I know why I am like this, not because of some sin (Gilberto)

Indigenous participants spoke in-depth about disability and how it was framed within their specific ideological and cultural settings. While it was clear that Catholic and Evangelical Christian narratives often overshadow local and community beliefs (see below), a number of participants mentioned instances where they had heard about certain beliefs expressed about their disability, in particular the cause. Most admitted that they had heard these accounts second hand from their parents who had been told something in the past by some or other community member. These beliefs also appeared to surround predominantly those with congenital impairments. As they recounted what they had heard, some half smiled, shrugging away such discourse in a context where people 'believe many things', while others reflected concern that even if these beliefs were fewer and fewer, they were still a worrying reflection of the isolated context they lived in.

Before mapping out some of these beliefs, it is useful to first identify the reasons as to why such beliefs about disability may exist. Reading through participants' narratives, a number of key factors emerge:

- Inaccessible or fragmented health care in remote areas means no precise medical diagnoses or only partial ones, and hence individuals may not know what their disability is. Traditional ideological beliefs may therefore come to replace medical labels and a tool to make sense of disability.

- Traditional healing practices using folk healers (*curanderos),* spiritual guides (*guias espirituales*) or *sobadores* (those who heal through massage work) remain widespread in indigenous areas, the latter in non-indigenous ones too. These traditional healers are sought for a number of spiritual and physical ailments and to ward off bad spirits. These healers also come equipped with ancient beliefs and rituals. In this respect they continue to contribute to the meaning of illness, disability and other material and spiritual conditions within communities. They are also more economically viable and accessible 'treatments' than Western medicine and may either delay or stop seeking formal health care.

- Some 75% of births in indigenous rural areas are still carried out in the home by local (not formally trained) midwives (*comadronas*) (CIA, 2015). Speaking about comadronas, participants mentioned distance to hospitals, costs, and general distrust of ladino medical doctors as key factors in their continued use. Traditional Maya rituals and beliefs prior to and following birth of the child can also only be attended to within the community and are still viewed as idiosyncratic to Western medicine.

- Communities are close-knit and highly oral: word spreads quickly, people talk to each other and are dependent on oral communication in contexts of deep isolation. In some cases, this word of mouth information is the only one they have access to. Absence of electrification means inability to have radio or television. While mobile phones have become more diffuse, reception is still low in remote areas, and poor people may not always afford mobile credit. As with most information by mouth, it may and is often distorted along the way. Overall, obtaining precise information is both taxing in terms of time as well as costly for those residing in the most remote rural areas. Traditional beliefs sometimes come to fill these gaps.

- Close communities may not always be peaceful, and rumours and gossip (*chismes)* are often rife. Participants mentioned with much frequency envy (*envidia)* as a major source of conflict, suspicion and soured relationships. In Guatemala, a popular saying is *'pueblo chico, infierno grande',* which translates literally to 'small town, big hell'. Beliefs, as participants suggested, may in this case be used as a tool of conflict.

- There is often little knowledge of disability on account of the absence of outreach medical and educational services including non-formal education. Community Based Rehabilitation (CBR) is still not known in most parts of the country.

- Barriers to work and schooling, harsh infrastructure and barriers in organisation (see below), mean that disabled people may not be too visible in public spaces. This is the case in both indigenous and non-indigenous areas. Communities may need to resort to traditional beliefs to make sense of them and their presence.

Overall, within such oral contexts, it is not difficult to see why traditional beliefs may contribute to framing disability. Asked whether they had heard any particular beliefs about them and their disability, indigenous participants did not often state clearly whether they did or not. Yet, a number mentioned two sets of beliefs:

a. disability a result of sin or wrongdoing by their parents- punishment by God;

b. disability resulting from the evil eye or a curse induced by someone else. I map these out below.

5.3.1.1 Divine punishment

Divine punishment is well documented in colonial Guatemala for acts such as adultery or crimes of passion among others, with illness and disease frequent punishments displaying the wrath of God (see Few, 2002; Matthew, 2012). What is evident in these documentations is how diffuse and how seriously these were taken in a climate of profound spiritual and religious doom. These beliefs were supported and perpetuated by European perspectives on sickness propagated through the Catholic church acting as vehicle and ideological/spiritual motive for the colonising/'civilising' mission. The

power of these beliefs were sustained by the church, because with divine punishment came also the power of healing, turning people towards fate and prayer in the hope for a miraculous cure. What colonial powers got in turn was submission and (self)control. To be clear, this did not mean no resistance by the Maya, and the continued practice of Maya religions in secret is a clear testimony of this (see Martínez Peláez, 2009).

Elements of these centuries-old beliefs continue to exist in present times. The notion of disability as a result of wrongdoing was documented by some of the participants, and this involved a supposedly sinful act committed by their parents, now being paid by the offspring. Two participants explained how community members tried to frame their disability within a broader narrative of judgement and blame:

> Yes, one time I was on the bay, there close by, and there were some people talking, I can't confirm it, but I'm almost sure they were talking about me and they were saying, 'he is like this because he is paying for the sins of his parents' (Andrés)

> In my life, when I was small, many would ask my mother: 'you have a disabled child' and my mother would start talking, and at times some would blame because… because of the mother or the father, this is what people say here. At times they say 'it is her mother's fault, or it is the father's'… but I do not blame anyone, because if God made me like this, this is how I will stay… (Carolina)

On one occasion, a disabled participant for example stated how his parents were told that their son (the disabled person in question) was born disabled because the mother had been 'a bad person' *'una persona mala'* in a previous or present life and that this was her curse. Asked what 'bad person' meant in this case, did not elicit a response. Another participant told how her father was rather distressed when he had heard that his only son had been born disabled as a punishment for his ill-treatment of someone else in the community. He went on to seek help from a spiritual guide:

> Many years ago, my father had argued with someone over some land many years ago, and in a fit of rage he was told by a family member of this man that he (father) was a bad person, and that that was why I was born like this. At the time, they knew little here, and isolated from everything, so he cried, not knowing if it was God or a curse. My parents went to search for the spiritual guide who performed a ritual on me...but he (father) then accepted it (disability) (Emerio)

This same participant, though, went on to explain how this statement was made in a fit of anger motivated by jealousy and envy over the fact that his father had inherited a small piece of land he could farm.

When probed, participants were clear in stating that they did not take these beliefs too seriously, and how these were overshadowed and even discredited by a more 'tangible' religious narrative- the will of God (see below). Andrés and Carolina went on to explain how they understood their disability in light of these beliefs:

> Without doubt I have never been in agreement with the comments made by these people. I believe that disability is not the fault of anyone. I have cerebral palsy because I had some complications at birth and this interrupted the flow of oxygen to my brain leaving permanent damage, that is the reason for my disability. Now seeing that everything happens for a reason, only God knows why he allowed this to happen, it is an injustice, but maybe it can

serve as an example for the rest living in conditions of disability to see that yes they can move ahead despite everything (Andrés)

People here only believe bad things, for example witchcraft...this is what people believe here. But I don't believe in this, because if I am like this it is because God wanted me to be like this (Carolina)

5.3.1.2 The evil eye

The second notion, that of illness or disability as a result of the evil eye (*mal de ojo)* or a curse induced by someone else too has a long lineage and history among indigenous populations, dating back to the colonial period and before (see Few, 2002). Indeed, there is ample documentation, and anyone familiar with the Guatemalan terrain in rural communities will have heard much about the curse (*maldición)* and the evil eye. The consequences of the evil eye include illness and injury or a set of misfortunes.

Beliefs in the evil eye are diffuse including in non-indigenous areas, and conversations with people will highlight an interesting dynamic, where even among those who reserve quite some suspicion or follow Catholic or Evangelical teachings, there is rarely an absolute denial of the existence of it. The evil eye among indigenous populations takes on very complex dimensions and manifestations in the Maya cosmovision. These include loss of the soul (*pérdida de alma*) where it is believed that the soul can detach itself from the body for example because of a traumatic incident. This is why there is so much attention devoted to *susto* (sudden fright) to refer to any incident or bodily sensation that alters the emotional state, the result of which may be a condition that weakens the body. These culture-bound interpretations mean that a range of conditions are framed as '*mal de ojo*'. For example it is believed in some areas that a child may fall ill because the mother is malnourished and is not able to breast feed the baby. In turn the child who is born 'weak', is impacted by contact with some person with a powerful gaze (*vista fuerte)* or with very strong emotions, for example of envy and/or who touches the child. The child has weak blood and the contact produces a disequilibrium in the body temperature, and which then results in fever, vomiting, restlessness and relentless crying. The belief is that *mal de ojo* cannot be treated by Western medicine. While this may alleviate the symptoms, it will not cure, and hence the person in question requires spiritual healing (see Randolph Adams and Hawkins, 2007). These beliefs and practices remain so diffuse and strong that in August 2016, the incoming Health Minister Lucrecia Hernández announced a new initiative where health centres will start attending to a number of these ancestral illnesses.

Participants and their families had substantial (and understandably so) reservations about speaking about these ancestral beliefs to a foreign outsider on short fieldwork. There was also reasonable suspicion around the motives for asking these questions, so conversations were focused on disability and through which I tried to explore with them these beliefs, if and whenever they emerged with discrete probing. Nevertheless, they spoke about the worries of their parents about the possibilities that something may have happened during pregnancy and that this may have caused their disability. Participants explained how their parents sought to find a reason for the birth of their disabled child, and ancestral and cultural beliefs were an immediate and cost-effective option. The most frequently articulated one was that disability could have resulted from sudden fright (*susto)* experienced by the mother during pregnancy. In some areas, this is considered an illness and requires treatment. Speaking to parents and children, it was clear that beliefs around the effects of sudden fright on the birth and development of the child do persist in communities. These include

sudden fright from seeing a feared animal (e.g. a poisonous snake), witnessing a violent incident, or experiencing sudden strong emotions. Asked what the effects of this fright are, they suggested that it creates anxiety in the mother, tilting the equilibrium of the body including its temperature. One mother explained how this affects the baby in the womb, and post-birth the baby may cry a lot and be very restless. She explained how during pregnancy she was startled by a falling branch, after which she fell to the ground and ran and then felt her heart racing, and which she thought at the time could have contributed to the disability of her child:

> My husband says that it was the branch, and I believed it too at the time...maybe….my heart was pounding and I then got a fever, and I knew that something happened, but I did not get treatment (spiritual healing) and maybe this was the reason why...the baby cried a lot when she was born...I don't know, there are many beliefs here (Mother)

The mother of another participant said that while she had her reservations as to the extent to which fright could have been directly responsible for the disability of her son, she nevertheless said that she did anything possible to have a calm pregnancy and not be subject to any sudden frights, including not walking on her own in the mountain for fear of seeing a snake. Having said that, she still mentioned the possibility of some '*mal de ojo*' she may not have known about.

Exploring in depth these issues, a curse induced by someone else emerged sporadically. Once again the data is inconclusive, but a small number of participants did mention the curse as another belief in what seemed to fall under the broader bracket of 'mal de ojo'. They explained how in certain communities it is believed that someone can cast the evil eye through feelings of jealousy, envy and anger and wanting revenge:

> For example if my father or mother argued with a neighbour...or if she had another lover, this is what people believe here...a curse...but I do not believe in this (Carolina)

Figures and saints such as the revered and popular syncretic folk saint Maximón (or San Simón) are emblematic of these beliefs and practices. Maximón, represented through a life size figure with a moustache, cowboy hat, smoking cigarettes and drinking alcohol draws many indigenous believers praying to him for all things and favours, including a job, a spouse, a cure for an illness, and most notoriously revenge. Speaking informally to communities, one will also realise that the risk of being cursed may among some people act as a form of self-vigilance and self-control, as one participant put it, 'a reason for not getting into trouble'.

The curse, though, is not one exclusive to indigenous areas. On one occasion during my fieldwork in a non-indigenous area, a young adult had collapsed and then started having uncontrollable seizures after which he was hospitalised. The community said his condition was deteriorating, and the reason, his family and some community members believed, was that someone had cast a spell (*una maldicion*) on him. I also had conversations with a number of people who said he was possessed by the devil. Doubt and speculation persisted over days, and the interpretations took twists and turns the more the story was recounted. Either way, the family were distraught and the hearsays that their son could have been possessed were met by anger and hurt. Speaking to the parents, they mentioned envy (*invidia)* a lot suggesting that in such a close knit setting, people often felt jealous or envious and wished harm upon others, but that this envy was also a cause for these rumours. They claimed they trusted the doctors' opinion more.

5.4 The Christian narrative: disability as the will of God

While the beliefs documented above were indeed present in certain indigenous areas (and most likely more intensely than evidenced here), the findings suggest that these are often confronted with, and even diffused by more hegemonic Christian beliefs and practices. What was interesting was that even participants who mentioned hearing these folk beliefs (e.g. that disability is a result of sin) subscribed to another narrative diffuse in this study- that disability is *the will of God* (see also Grech, 2015). The following quotes are illustrative:

> My being like this is the will of God, and only he knows what his plan is for me (Mauricio)

> I put all my trust in God because he gave me this, so I live my invalidity because I believe in him (Estela)

This is perhaps unsurprising:

- Catholic and Evangelical Christian religions remain strong and are growing in Guatemala

- Temples and churches of worship are more present in isolated rural areas than government or health care facilities.

- These influence world-views, customs, and even trends in communities. Religious beliefs also impact understandings of vulnerability, illness, disability, poverty and other conditions, and in turn shape social responses

God, as participants recounted is benevolent and has a plan, making their disability part of this plan as opposed to being a curse. While this did not necessarily alleviate the view of disability and its consequences as tragic, disability was framed as 'destiny' or something that was meant to happen because God wanted it. In turn, and despite the hardships, the only thing they could do was accept it and all that resulted from it, and seek recourse to God and prayer:

> People were envious of me, they would call me a 'blind donkey', that I was 'bind'...they would throw stones at me...my mother would tell me 'have patience my daughter, anyway it is God who made you like this, so what are you going to do?...and what I would do was cry… 'They are making fun of you, but some day' my mother would tell me- 'you do not have to be like this, because God is seeing it all, because the reason you are like this...so leave it my daughter and pray, pray' (Juana)

The positioning of disability as the will of God also had implications for how participants felt disabled people should be seen and 'treated' by others, even if this in practice was not always the case. Evangelical Christian and Catholic teachings promote goodwill and charity especially towards the weak and vulnerable. While participants did not always encounter benevolent attitudes and behaviours (see below), they felt that disability was mapped out by God, and on the basis of this, they deserved compassion and charity from others:

> Jesus helped the poor, those without hope like me, so if people are to be really Catholic, they should know that they have to help and respect and not taunt and make us suffer...this is what the priest tells us (Roberto)

What was evident was that God became an interpretive framework through which to process and indeed negotiate the onset of an impairment, the reason for it and its consequences. For participants, God and faith became critical in:

- the process of psychological and emotional adjustment following the onset of impairment or at some point later in life: in rural areas there are no psychologists and few if any organisations to help support with this. Churches, priests and pastors frequently fulfil this role.

- negotiating the various traumas including loss of livelihoods, extraordinary pain and the dramatic impoverishment borne by them and their families.

Unlike medical care, faith as participants stressed, was immediately available and it came for free. A number of participants claimed they were not very religious, but expressed how at some point they felt pushed towards God and religion to find meaning and comfort, to adjust, and in some cases in the hope for a cure (see below):

> Some years ago, my spiritual side was not so developed, because of the circumstances I lived through, but at some point I felt the need to look for God, even if this is not the correct way of saying it...because God looks for the person, the one who needs help. And so I got closer to put it this way and it changed completely my life, my way of thinking, and I believe this is why I have a more positive view of myself, of life. And so I can take problems that afflict me in a lighter way...I add it to the most important thing in my life (Andrés)

As a result, many had joined a church or temple. They also suggested that this turn towards religion was also influenced by family who themselves were trying to find meaning and looking for moral and emotional support. The turn towards a congregation also had practical dimensions. Many recounted how going to mass or worship (*culto*) on Sunday was often the only time they left the house. In a number of cases, participants recounted how members of their congregation would go to their home and physically carry them to the church on Sunday. These congregations were also a safety net in times of crises. It was not unusual for participants to document how church members would collect and pool money to help get the disabled person to hospital in an emergency. Though not regular (other members are generally poor themselves), they constituted critical help in times of serious despair and absence of alternatives.

Overall, these perceived positive benefits reinforced the importance of faith. They also pointed participants and their families sharply towards the practice of prayer- a critical source of comfort in times of particular hardship, for example when their unmedicated pain became particularly unbearable, or when the financial costs were just too high:

> I pray to God to give me strength, to lessen the pain, or for someone to come and help me. God has to watch over me, I pray to God because only he can help us. I am always praying to God...to watch over us, for all the suffering we bear, the poverty, the sadness (Juana).

> I would read my bible and pray to God that it would be the last treatment because I didn't have money. Because it was a lot I was spending, almost Q8000 (Santiago)

Prayer in some cases was also transformed into a plea for a cure. Despite the fact that most of the participants had fixed and even degenerative impairments, hope was the last thing to die, even after years. Some claimed to pray for a miracle to happen through divine intervention, others prayed for discovery of a medical cure, and others still (a minority) scheduled for some medical intervention prayed that this would lead to complete recovery. The same poverty and misery they and their families were cast into, meant that praying for a cure was the only thing they could cling to, however unrealistic this was. They prayed to recover enough strength and agility to be able to return to work, to farm and grow part of the crop, to feed their children. This participant with a degenerative condition expressed his rather unrealistic hopes:

> Look, what I think is...I would like the operation to be successful...even if I will still be poor, but to be ok (physically). To earn my living another couple of years. I have strength to work, but what keeps me screwed up is this (touches knees)...cured from this, I believe that I can still earn my living anywhere (David)

5.5 Diverse social attitudes and responses: a spectrum

A range of literature in disability studies, especially that inspired by social constructionist perspectives, suggests that disability is not a result of biological limitations but is instead an outcome of discrimination and barriers imposed on people with impairments (Oliver, 1990). This has contributed to serious shifts looking at rights and empowerment of disabled people and their organisations as opposed to charity or medicalisation.

Evidence from this study, though, suggests that social responses just like disability, are not homogeneous. They are also not necessarily negative or exclusionary. Instead, social and attitudinal responses seem to:

- Operate along a spectrum, and can be both positive and negative
- Not suggest systematic stigmatisation of disabled people
- Be contingent on the type of impairment, personal and family circumstances
- Be dynamic and indeed can change over space and time

The first point highlights an attitudinal and behavioural landscape that is diverse and that challenges simplistic and deterministic dichotomisations (e.g. inclusion vs. exclusion). The findings in fact contradict hegemonic discourse that disabled people are all subject to discrimination and marginalisation. They also do not support notions that all disabled people are stigmatised. This critical perspective by one participant captures this scenario:

> You cannot put us all in one box. I have never been discriminated, but X down the road has a very serious disability, he looks and moves in a strange way, so people sometimes call him names, but I don't think they do it to offend him...now they know him so he doesn't get offended...they laugh but they also help him...its complicated (Wilfido)

Interviews in fact document a range of attitudes and social responses that cannot easily be placed in any category:

- Acceptance
- Support

- Companionship
- Ill-treatment
- Taunting
- Indifference
- Discrimination

Asked whether they felt discriminated and excluded at some point, most of the participants replied affirmatively, though they suggested these attitudes were not always motivated by the will to exclude and harm. Instead, findings suggest they may well be the result of:

- Profound lack of knowledge about disability and lack of education and sensitization within communities
- Unfamiliarity with the sight and presence of disabled people in communities: whether on account of remoteness, infrastructural barriers or transport hurdles, disabled people are not too visible in communities. As a result, their presence is hardly normalized in rural areas.
- Close-knit and slow paced contexts: there is often not much happening in terms of social engagement and leisure activities. Anything 'out of the ordinary' therefore becomes almost hyper-visible.
- Shared desperate conditions and poverty: the struggle for survival sometimes pitches people against each other, whether to compete for work or to mobilise in chaotic crowded spaces e.g. rural markets. Disabled people are as a result not granted many concessions or positive discrimination.

Reflecting further on the points above, what perhaps emerges is that negative responses are ultimately symptomatic of deep structural inequalities in the midst of political indifference, educational gaps and isolation. Poor communities are left to their own devices, and this includes how to interpret and 'deal' with disability. Participants spoke about the hurdles they faced in earning a livelihood, and felt that they were severely disadvantaged and even discriminated when it came to engaging in any paid labour, for example casual agricultural labouring. They spoke about multiple obstacles, not only physical ones to performing labour activities, but also attitudinal ones. For example they told of how they were blatantly refused and not given a chance to do casual agricultural labouring because they were perceived as too slow or unable to engage in these tasks. Asked whether these responses were based on their disability, participants responded that these were based on the fact that they were disabled, but that they were also to an extent understandable. They explained that most tasks involve strenuous labour, which they admitted they weren't quite sure they could perform or sustain in practice. They also highlighted (see above) how most community members are in desperate need to work themselves, which in turn means that poor people are constantly in competition with each other. Though the greatest hope for most of the participants was to find or resume their work, they also explained how within this climate of collective need, it was better for labouring activities to sometimes be taken on by non-disabled people who could do them better, especially their own family members, because this labour would have ultimately helped support them too:

> My brothers can do the work, so I benefit too...give it to them, because we are all struggling here day to day...the struggle to live, to eat and not die every day until God calls you (Anselmo)

This, though does not mean that negative and even harsh attitudes and behaviours do not exist. One participant who drove a bus in the department head was shot because his employer at the time had not paid the protection money to local extortionists. He documented in detail how he had been

warned and relayed the message to the owner of the bus who said that he had paid the money. The following day he was shot. He lives with spinal injury and can no longer work and has since then returned to his family in his native rural village. His employer had no obligations towards him, since the work was unregistered, and any pleas for financial or other help were blatantly ignored by the owner of the bus who then abandoned him completely. Not only, but he tried to discredit him by spreading the rumour that he was shot because he was having an affair with someone. He explained how he became useless, and like others, disposable. And returning to his rural village, meant there was no work.

Other participants told various narratives where they were ill-treated. These included unresponsive or even aggressive municipal offices in response to disabled individuals going to ask for help (financial or work) in times of material despair. Others explained how they could not complete their education because they were blatantly refused in schools. One participant, a woman with a visual impairment recalled being called names as an adolescent, taunted by children who even would throw stones at her.

Families too are not necessarily unitary, sharing or harmonious. Participants did document incidents of internal conflict and even ill-treatment by some or other family member. In one instance, for example a participant spoke in-depth about what she called the 'envy' of her siblings after the local priest built a house for her and her family. Her siblings, who lived next door no longer spoke to her, and when they did, subjected her to constant ill-treatment and even spread rumours about her:

> The priest gave us a house because we were all exposed, dirt, mud, people know we are the poorest here. But this was the worst thing, many times I cry and think how can we sell it maybe. They (siblings) turned my mother against me, she no longer talks to me, I just cry and cry, and my brother spat at me and my husband...we live in fear and it pains me (Dolores)

The most negative common response, though, appeared to be indifference. Participants spoke in-depth about almost broad based indifference towards them and their presence. They highlighted how people for example would not move up or offer their place in a bus. They would also ask for help in a busy town and noone would respond. This indifference, they suggested, turned to direct negative reactions when their presence met and imposed something on others. For example, participants mentioned being seen as a burden or 'in the way' in busy spaces such as market places, and how hawkers and shoppers would tell them to move out of the way or to go home and that those weren't spaces for disabled people. They documented incidents of not being allowed to use public transportation in villages, especially the minibuses (*microbuses)* scouring the dirt tracks. This was especially the case for those with low mobility and in particular those using a wheelchair. Buses would not stop for them, or blatantly refused to take them on because it would have slowed them down. If they did, some would charge them higher prices for loading the wheelchair on the roof and carrying them in. Many in fact had to resort to using a private driver with his own vehicle that came at a much higher cost. For most, barriers in transportation meant entrapment in distant villages for extended periods and also inability to access health care in emergencies.

Overall, these negative attitudes impacted not only their material situations was also their emotional state. Many highlighted how they felt demoralised by these reactions, and even angry and frustrated:

> ...one feels abit bad, because at times he is not expecting something like this from other people. One always expects that they would give encouragement instead of lowering his

self-esteem, better to encourage someone so that he can move on...but people do not know, better all interfering in someone else's business (Roberto)

5.5.1 Communities of support

Overall, though, even those who mentioned encountering negative treatment at some points, had quite a few stories to tell of positive attitudes and support, without which, in the midst of political indifference, many admittedly they would not have been able to survive. Disabled people in the study mentioned confronting a range of behaviours they called 'kind', 'friendly, 'caring' and 'charitable', especially those manifested during times of crises such as ill-health.

Participants explained how with no formal safety nets, and often with no organisations in sight, the only means of survival are ultimately their families and communities- other poor people- and the little they have to share. This includes dependence on charity and handouts, in particular small amounts of money and food. An interesting finding here is that participants, especially those who had had no contact with a DPO (the majority) almost unanimously did not have a problem with charity. They also did not see this as disempowering as it is by urban disability activists. Instead, most were not only supportive, but actively encouraged it. Charity, it was clear, is not a dirty word for the poor as it is among privileged urban stakeholders who can afford to demonize it. While many stated they did not actively beg for money, they expressed how these handouts framed as 'gifts' (*regalos)* were often life saving, especially when they needed emergency health care, or when they had no money to buy any food. In turn they expressed feelings of happiness and felt loved and cared for.

Participants documented a range of situations where they received help and much support, including emotional and economic support. They spoke about the words of comfort from family and friends following the onset of their impairment. Communities sometimes raised money in times of a health emergency. They also mentioned their dependence on erratic food handouts by neighbours, for example a pound of bean and corn here and there when they knew the family was struggling (e.g. prior to harvest). The following narrative demonstrates the breadth of this support:

> I have always found some help, even if a few cents or two tortillas when people knew we had no food. I like it when some people give me some money because like that I suffer less, and I say 'thank you' because I know that some people care about me, they love me...many people from the village have shown affection towards me...they tell me 'do not worry, for food do not worry, just come here, and even if we do not have tortillas, we will give you corn, and if not, we will give you bean'...if they give us at least corn, we will manage at least with the tortillas. And like this we go on...and one time...there was a woman who owns a shop, she was giving milk and *Incaparina to* my daughter so that she would have food. And thank god today she is already grown up (Juana)

Having said that, the narratives are clear in suggesting that inequalities are rife even within rural communities, and that ultimately, and despite their limitations, help is more likely to come from other impoverished family and community members than from wealthier ones e.g. municipal authorities and their associates, landowners etc. The following quote captures this:

> The person who has (money) and who wants to help sick people, those who are old, who need it, is rare. It is rare to find people who feel pity for the neighbour. And there are people who have money with which to help, but they are not interested in the life of the other poor person. Since they are eating, drinking, handling money...Here there are people who have

cash but even if they see one ruined they will not tell him/her: 'hey what do you need?' 'Do you want me to help you with anything?'...No...nothing of this (David)

Overall, the stories are ones of extensive hardship, but also support, and importantly of attitudes that are heterogeneous as well as dynamic- they do change over time. Participants recounted experiencing negative reactions that changed over time once the person in question got to know them, or once the church acted as an intermediary and connector. Importantly, they were emphatic in suggesting that positive attitudes and perhaps even benevolent responses were bound to the extent to which others saw them as 'good people' engaged and committed to the struggle (*la lucha*) to survive despite all odds and the limitations imposed by their impairment. Some spoke about feelings of pity (*lastima*) that were not perceived as negative or condescending, but instead as manifestations of humanity, especially when these feelings translated into concrete support and giving. This, though, was not the situation across the board and a number of participants especially those who had contact with and/or were part of a DPO were more concerned about personal attitudes and shifting those of others.

5.6 Policy, organisational and service vacuum: the limitations of rights

Disability and poverty cannot be removed from the institutional context. Indeed, they can perhaps only be understood within spaces of deep structural poverty, inequality and neglect. I map out these in the following subsections.

If there is one aspect that perhaps defines these complex rural areas, it is the stark absence of institutions and organisations operating within these areas. Narratives from participants and their families are replete with frustrated expressions of how politicians do not care about poverty and the poor. Politicians visit these areas for the vote and they scurry back out, leaving behind only false promises:

> Many politicians offer things, but once they have won and are in their seat, they will not deliver on the things they offered...the mayor of this town who won the elections this year, offered many things… he promised to help children, street children, promised to do football grounds, and also promised to help disabled people...but what we are seeing now, is that he is not doing anything (Carolina)

Municipal authorities are often the only semblance of government as well as notion of 'organisation' (apart from the church) that the poor do know, but these:

- Are often simply a means of personal enrichment and support for wealthy associates: community development, creation of industry and employment, accessible health care, and decent inclusive schools do not seem to be priorities. Corruption, mismanagement and blatant robbery of funds are rife and open for all to see. When a minor one-off program appears, for example distribution of food packs for the poor, corruption and co-option take over. During the fieldwork, the municipality in one area was responsible for selecting impoverished families and delivering donated food rations. Unfortunately, as many lamented, they were instead given to wealthier people including livestock farmers who used the corn as feed for the cows. These wealthier people are often powerful associates in contexts where politics of favours dominate:

> It has happened, it is people with more money that they help. Because I imagine they say 'if we help a poor person, when elections come, how will it benefit us?', and so a rich person will receive favours from them, and they will help him. For example, they go to a village and choose the one with the most money, because when the time comes, this same person will support with money...they sent some help, some maize and other things. The people were complaining because they (municipality) gave them to estate owners, and they gave the maize to the cows as feed. And the people who maybe need a pound of corn to make their tortillas and sustain their home, to them they give nothing (Mario)

- Are not always knowledgeable of national policies (including the disability law) or international declarations and obligations (e.g. the CRPD) and are not obliged to implement them. Importantly, they are not monitored by central government.
- Have no interest or obligation to create social and development programmes- poverty is not a priority. Any social initiative is at the discretion and initiative of the mayor. Over the course of the fieldwork, I witnessed rare cases of 'support' by mayors. These included handouts of small amounts of money or assistance with offering the municipality vehicle and driver to individuals in an emergency to reach a hospital. This support, though, depended on the mayor offering help and was perceived as an act of 'goodwill' as opposed to a duty or responsibility of the authority. As with all random and personal initiatives:
  - they often cannot cover or reach everyone and may even discriminate
  - they are erratic and inconsistent
  - at some point they are terminated

  > He (mayor) put his hand in his pocket and gave me Q100. 'Take it' he said 'to buy your medicine'...He came and gave me another Q100, but it was out of his own will, I did not ask him for anything. It was purely his will, out of pity, he saw I was worried, was all screwed up there...but then that's it (David)

- Services such as health centres and public schools remain deeply under-resourced, unequipped and stretched.

Organisations, including national and international organisations, including DPOs and associations are nestled in the capital city. Much of the discourse that is developed within this space, strategies and programmes are disproportionately focused on urban areas, and rarely have poverty and poverty reduction as a key focus and component. There are few if any outreach programmes, and indigenous populations and areas are particularly excluded. Even more importantly, as the interviews attest, disabled people have scarce or no knowledge of the existence of these organisations, including the national disability council- Consejo Nacional para la Atención de las Personas con Discapacidad (CONADI).

While small DPOs and associations may exist in rural towns, they are not only very rare, they also may face a range of barriers in policy advocacy and service development:

- They are composed of relatively poor people: this means that members cannot meet with regularity, cannot visit disabled people in dispersed areas with regularity, and cannot build a critical mass
- Lack of resources (e.g. to pay for transportation) and distance mean that they hardly participate in debates on disability, such as those held within the disability council (CONADI) in the capital city or they only do so intermittently. The departmental commissions (CODEDIS) also seem to have very limited reach and participation where they

do exist. Issues of rurality, poverty and indigeneity are therefore often relegated to the background or ignored and the interests of poor rural disabled are rarely adequately represented and prioritised.

- Lack or absence of funding and technical knowledge, mean that advocacy and service provision are seriously constrained
- For those engaged in some or other service, for example engaging disabled people in crafts and artisan work, low demand meets low spending power, making these activities scarcely profitable and unsustainable.

In an informal conversation, the leader of a small rural DPO explained some of these aspects:

Those in the city do not care about what happens here, and therefore it is ok to ignore us. We do not have money so what we can do is very limited. And what we try and do is constrained by the fact that people do not have money to spend. So if we get people to do some crafts and try and sell them, they will make almost no money and then give up. They are also more concerned about how to cover their health care costs.

5.6.1 Policies and rights on the ground: distant discourse

One emerging finding is that poor people, including disabled people are rarely aware of policies and rights discourse and measures. However much was invested by the disability council in printing the CRPD or promoting the disability decree, these initiatives and policies are not known by poor disabled people and their families. They also may have little relevance or currency in these lives whose main concern is survival. To summarise some aspects:

- Policies are drafted, promoted and celebrated in the capital city with much fanfare, but there are few efforts in making sure they are disseminated in accessible ways and even known in rural areas. Many poor people also cannot read. More importantly, they are not adapted to the needs of the rural poor, and rarely guarantee any immediate outcome.
- Policies are hardly known, implemented and monitored by municipal authorities themselves (see above). They are also untrained in disability and/or other social issues.
- Policies may be there, but are regularly flaunted by governments and powerful stakeholders: corruption and impunity are a daily and known narrative and accepted, by rich and poor
- The poor are consumed by immediate needs and demands (survival), leaving no time or even resources to obtain information on policies

Even more practically, poor people have little fate in institutions and governments as well as policy. Indeed, if nothing ever shifts in their immediate poverty situation and their deprivation, policies are as good as the paper they are written on. The following quote captures these concerns and views of government and policy:

Here in Guatemala, they (governments) do not take you into consideration, as a disabled person, no, they don't give much attention...it is like one doesn't exist. How many disabled people are there in Guatemala, but they don't give attention. I was watching on television how there are I don't know how many disabled people in Guatemala. And the budget is only 13 million Quetzales, but how can they help one when they do not even remember about one...and so this money they do not give it to anyone, but pocket it...in the pocket, from there, nothing comes out. Because even if it is not a lot of money, they don't give it to

anyone… they are the keepers of this money….things on paper are many, but what we want is to be able to eat (Geovani)

The findings highlight not only the limitations of policies but also of rights discourse on the ground, or rather the extent to which poor disabled people can claim their rights and seek redress in contexts where rights violations are a daily, accepted and often uncontested reality:

- Dramatic poverty, inequality, vulnerability and even hunger are clear and almost accepted and normalised rights violations. They are unshiftable.
- Disabled people, perhaps like many other poor people have little or no knowledge of what their rights are or even laws, whether on account of distance or lack of information
- Disabled people do not have the resources or means to know their rights and/or to seek redress: this includes money, legal advice and supporting organisations.
- Their voices and testimonies are at times discredited in the case of injustices on the basis of their impairment
- Where good governance is lacking, violence and fear are rampant, and poverty persistent, human rights, including those enshrined in the CRPD translate into very little, if anything at all on the ground.
- Fear, oppression and lack of resources among local and national organisations constrain political mobilisation and advocacy. This situation is compounded by lack of engagement with and support for rural NGOs by those working within an urban context. The poor too are often effectively silenced and fear used as an effective tool by powerful stakeholders to curb resistance.

The following narratives clearly map out this landscape:

Well, I I don't know anything about laws...those of us who live in villages in the countryside about laws, it is not like for those in the capital city, it is like people here are not so aware of what benefits them. Only sometimes when they see something on television, or they report something on the news that people say 'one has to support this or no'...this is the life here in the village….one cannot say that people know: 'look there is this law and...with this law I am going to do this'. And so no, at times because of fear, they say 'they get used to living like this'. Those who work, from work to home, go out a Saturday or Sunday here in town or some park. This is what life here is like in town. It is not about going to protest about something...because of the same fear...people here do not get involved (Mario)

In my opinion, I see that no, rights are not respected. Because one can see we have a disability and that we also do not speak well, they do not pay attention to us when we are speaking, who are we going to believe? Once I had problems because a man went to accuse me with a judge, and what happened was that they did no believe me, but him they believed...the word 'rights' is pure rubbish (Carolina)

5.7 Conclusions and Recommendations

Reflecting back on the key findings in this study, it is possible to draw some conclusions. These are summarised below:

- Poverty and rural contexts are complex, heterogeneous and dynamic. Across cultures (even within one country), defining disability is complex because it is diverse and heterogeneous. This means that any standardising, generalising and authoritative discourse on disability may be both erroneous and ill-informed.
- The boundedness of disability to the poverty context calls for serious efforts at learning about and from these complex poverty spaces at the most micro level, and how life is lived on the ground. This cannot be done from a distance.
- While disabled people confront specific needs and barriers, disability impoverishes further by intensifying common and shared barriers. This draws attention once again to the need to engage with the nuances of life in poverty at the intersections of the micro, meso and macro.
- Disabled people may not necessarily feel excluded or discriminated. They also confront complex and heterogeneous cultural beliefs and attitudes and social responses. Persistent negative views and generalisations by outsiders run the risk of occulting and even threatening the support, love and care of family and communities. This does not mean ignoring or not addressing discrimination and oppression when they do exist.
- Disabled people, like other poor people confront a scenario of political and institutional void or at best fragmentation. This calls for contextualised and critical evaluations of policies and programmes on the ground.
- Rights, including disability rights and conventions matter very little when they are hardly known, when the poor confront insurmountable barriers to claiming them and seeking redress.
- Disabled people and their families have only themselves and their communities- other poor people- to depend on and survive despite all odds. This in itself is a reflection of their tremendous resourcefulness.
- Broad based poverty constrains the amount of care that families and communities can provide. The implication is that targeted disability policies, conventions, and strategies, are unlikely to succeed if the poverty, inequality and well-being of all poor people irrespective of their disability status are not flatly addressed.

5.7.1 Recommendations

To round off this study, a few tentative recommendations can be offered:

- Disability is experienced, understood, negotiated and renegotiated over space and time and transcends the individual. This calls for disability research that is longitudinal; that has a family focus; that looks at the impacts of disability in intergenerational ways; and that accounts for the heterogeneity of the disabled population within diverse ideological and religious spaces.
- A twin-track approach may be beneficial by seeking to include disability in mainstream strategies and programmes (e.g. poverty reduction), as well as having programmes that are specific and targeted at disabled people. Within this, targeted programmes need to account for and be responsive to the specific yet changing needs and circumstances of rural families rather than adopting blanket one size fit all 'solutions'.
- Rural stakeholders must be heard, their voices must be prioritised and must own the process. This can only be done through an open and inclusive process of representation.
- Policies and services looking at disability need to account for and target families. Stronger families mean enhanced well-being for the disabled family member.

- Targeted policies and services will have limited impact and are hardly possible if the broader needs of all poor people, whether disabled or not, are addressed. Better roads and accessibility, better access to food, affordable health care benefit everyone, including disabled people. Communities of support need to be strengthened and any obstacles to the support they can provide to disabled people and their families removed. This includes their own poverty.
- In relation to this, it is safe to say that a system of universal social protection is urgently required to ensure basic levels of consumption and even survival across the board.
- Real access to rights on the ground rests first and foremost on good governance and removing any obstacles to its achievement. Measures such as the CRPD and national disability laws need to account for critical issues and problems in governance at the most local level, drawing a more realistic evaluation of what is objectively achievable or not, and to invest in understanding, shifting and removing hurdles.
- Policy makers and local governments need to be educated about disability, and an effective system needs to be in place to monitor and evaluate the implementation of policies.
- NGOs operating in the capital city need to inform themselves, learn from and form effective alliances with their rural counterparts, support (including financial and technical) and empower them in the collective struggle as genuine partners.

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