‘Hacemos lo que podemos con lo que tenemos’

La vida diaria de las personas con discapacidad y el largo y complicado camino para mejorarla en Pando Bolivia

English title: ‘We do what we can with what we have’ - *The daily life of people with disabilities and the long and complicated road to improve it in Pando Bolivia*

Cecilie Kyed Reese Andersen. Social Anthropology: Master’s (Two Years) Thesis – SANM03
Spring Semester 2023. Department of Sociology, Division of Social Anthropology, Lund University
Supervisor: Alexandra Middleton

Abstract: In the search for grasping how the everyday life experience for people with a disability is shaped in relation to the local social and political complexities in Cobija/Pando four themes are crucial to understand. Firstly, illustrating how the rhetorical definition of disability removes the wrongfulness or responsibility from the shoulders of the individual to an exclusive social environment. Even though this definition helps with empowerment and self-worth in reality the responsibility for changing the exclusive society is placed back on my interlocutor's shoulder. The study highlights the most essential creative tool for the purpose I found to be the family and their willingness to do care work. Constituting the smallest economic and political unit found within the society, but at the same time the highest ranked in terms of responsibility of care, thereby becoming the unit of survival and solution. Thirdly, research shows that as in other low-income countries disability being the last to get a job if any opens, not getting to the hospital in time because of transportation costs, not having the money for the operations needed, or being kept from education because of lack of resources. Problematic for the general population, but even more so for a vulnerable group like people with disability – creating poverty within poverty. Finally, the need and value of organizing and collaborating in the Pando Department are evident but my research showed the practical difficulties of mobilizing people and the emerging internal conflicts. It shows the difficulties of having a diversity within unity. It is a mirror of the general complexities of social and political life in Cobija/Pando and shows that not every disability category has the same opportunity or position to fight.

Keywords: disability, poverty, family, intersectionality, mobilizing, social anthropology

Acknowledgement: Firstly, I would like to give a huge thanks to Henry from DHF and Eduardo & Nancy from their Cochabamba office for letting me participate in their pilot project in Pando and use it as an entry point for my fieldwork. My study and thesis work would not have been possible with their extensive work and help in terms of facilitating contact, support, schedule planning or help finding recommendation in Cobija. Secondly, I would like to thank the people within the commission of the pilot project situated in Cobija. Receiving me with open arms and including me in all their activities with great joy, support, and interest in my focus of study. Sharing their experiences, perspectives, bringing me along to the other municipalities, introducing me to the other people within the disability community, inviting me to your homes or to participate in social events or activities. Thirdly, all the people and my interlocutors I met and engage myself with within the disability community in both Cobija and beyond. I am so moved and humble of the trust they shoved me by letting me in and sharing their personal stories and experiences – both the struggles and the happy times. This fieldwork experience and the people I talked to expressing joy and appreciation of being listened to means more to me than any given grade I could receive for this paper. Fourthly, I would like to thank the people who became my homebase – my caring Bolivian grandmother Señora Maria and my passionate knowledgeable Italian roommate Stefano. Furthermore, thanks to the colleagues of Stefano working in the Secretaria Departamental De Gestión Integral De La Madre Tierra for embracing me and letting me participate in their social events or activities – 'La Cripta no se va'. I feel so honored and lucky for this whole experience and Cobija/Pando will always have a special place in my heart – especially because of the people living there. Finally, I would like to thank my supervisor Alexandra for all her help and support during this thesis and fieldwork period. Your work has been beyond what is acquired of a supervisor and your always positive and excited on my behalf energy has really helped me believe in myself and my study. It has meant the world to me, and I have really enjoyed having you as my supervisor. So, a thanks is hereby directed to everyone who has made this study and experience possible!

Table of Contents

Chapter 1: Introduction

In January 2023 from the city center of Cobija, a pilot project emerged. Set to last a year with the purpose of passing a new and better law package for the people with disability in Pando: travelling to all the 15 municipalities within the region to socialize these new laws, empowerment, encourage the people to organize, and to promote dialogue and leadership within and between the already established associations for people with disabilities. In collaboration with the Danish Association of Physically Disabled people (DHF) and their Bolivian office, a commission had been formed consisting of people working within the disability sector in Cobija and all the five voluntary working presidents representing one of each type of disability association. Pando was chosen because it is the most mobilized and united region in terms of having associations for the different types of disabilities, and only one Federation for the whole Department. Despite the advance in mobilization within Pando the different disability types often work in monoliths and therefore the project's additional focus was on dialogue and collaborating as a common voice. Interestingly, this pilot project is the first time the institutions and associations within the area of disability are collaborating here.

My interest in disability as a field of study started during my internship at Disabled People's Organizations Denmark (DPOD) last fall. In my work here and writing my reflection paper for the university, I found out how forgotten this group of people was not only in the eyes of the general population, the government but also within the field of anthropology. And even though an increasing anthropological engagement with critical disability studies can be spotted, studies being conducted outside the context of "the Global North" or with the focus on the everyday life experiences and stories from people with disabilities are still under-represented. Combining disability with my interest in Latin America this became my subject and field site of interest for this master thesis. Aiming to focus on personal experiences and the performance of agency by the people living with a disability. As the only Danish disability organization collaborating with countries in Latin America was DHF, the Pando Department of Bolivia and their pilot project became a given entry point for my fieldwork.

The Pando Department lies in the far north-west corner of Bolivia and is a part of the Amazonian part of the country (Appendix, Map 1). It is a department spreading over 63,827 km2 of land, but with the low population density of only being 154,400 people to populate it (Wikipedia 2023c). Within the Pando 1510 people is registered to have a disability. The headquarters for the project was in Cobija, which is the only major city in Pando (78,555 inhabitants as of 2020, 988 with a disability). It is the municipality with the densest population of people with disabilities and therefore the people with disability within Cobija has the everyday life experience of the best organized associations, programs, special education options possible within Pando and a rehabilitation center called Miky Maia. The people living with a disability situated in the other municipalities must often travel the long way on orange clay road to Cobija to acquire the needed help. Thereby, experiencing how forms of power like poverty, infrastructure or lack of political interplays and influence with their lived experience of disability on a daily basis (Eide & Ingstad 2011). Additionally, family constitute the smallest political and economic unit. Though due to high political corruption cases and disinterest in the area of disability, the unit of family is higher ranked than the government in terms of the responsibility of caring for one's own (Ma 2019).

Wanting to explore how the setting of Pando interacted with the everyday life experiences by the people living here with a disability, the purpose of this thesis is: to explore everyday life experiences of people living with a disability in Cobija/Pando, Bolivia and to examine what the lens of living with disability can tell us about the complexities of social and political life in this region. In this exploration, I am interested in the interactions between local *discursive framings* of disability and the *material conditions* of everyday life in Cobija/Pando. To encapsuled this, my overarching question will be:

What is the relationship between everyday life with a disability and the complexities of social and political life in Cobija/Pando?

Guided by preliminary research and my own findings while being in the field, I found the themes of the local discursive framings of disability, family and care work, the intersection of other material conditions and the access to mobilize as being the most vital to investigate and dissect in order to answer my overarching question. I have therefore constructed four sub-questions to guide the unfolding and analysis of my empirical material in their own individual chapter through this paper. The sub-questions I will engage myself with to answer the overarching question is:

1) What constitutes 'disability' in Cobija/Pando—as discursive category(ies) and lived experience?
2) What role do family play in caring for relatives with a disability and navigating the public sphere with a 'difference'?

3) How do material conditions (i.e., lack of governmental assistance, poverty, infrastructure) shape the everyday life experiences for people with disability?
4) How people living with disability mobilize politically within their local political systems?

This thesis will be divided into 5 chapters. In continuation of this introductory, a brief background of the different associations and institutions, I will be referring to through this paper. Then a section where **preliminary research** will be explored and discussed – focusing on how and why these are relevant and helps legitimizing my own focus of study. Following, a section of **theoretical framework**, where I will argue for why these theoretical concepts are useful and how I attend to use them to analyze my empirical material. Afterwards **methodology** where the how, why, and what can it tell me concerning my choices of the anthropological methods I brought with me into my fieldwork will be answered. The final part of the introduction chapter will explore reflexivity and ethical dilemmas. **Chapter 2:** Will explore what constitutes 'disability' in the context of Cobija/Pando, the constructed categories and how the negative terminology affects their lived experience. **Chapter 3:** Discuss disability is a family lived experience and how it can become either the solution or the problem for the person with a disability. **Chapter 4:** Explores the concept of intersectionality and how poverty, lack of political engagement and infrastructure all intersect and influence a person's experience of having a disability. **Chapter 5:** Here the issue of political mobilization based on your disability type, the tension and inequality it can create and thereby causing difficulties in terms of collaboration across categories. **Chapter 6:** Will be a summary and conclusion answering my overarching question with afterwards meta-conclusion and future research.

Background

Due to the political background of The Pando Department being situated in the opposition to the government and therefore the region only receives the minimum of governmental help. Therefore, the focus of the pilot project is to improve the legislations on a departmental instead of a national one was that in Bolivia it is hard to generate any national change if you do not have the same political colors as the political party in the

The Commission

government. One of the important benefits of people with disability in Bolivia is the right to a house free of charge by the government. There have not been constructed enough for everyone, but three barrios (Appendix, Map 2) on the outskirts of Cobija have been constructed after appealing was made to local authorities. Institutions working within the disability sector is UMADIS (social office for the municipality of Cobija), CODEPEDIS (the Pando filial for the national organization for people with disability) – both the directors of these local offices are a part of the commission. Beside them the commission constitute of the president of the Federation (the centered leader for all the associations within Pando) and the president of each of the five associations all representing and promoting their different type of disability – *physical, visual, auditory, intellectual, psychic/mental*.

Preliminary Research

"Given the centrality of diversity to our epistemology, why has the subject of disability not been a key topic for our discipline?" (Ginsburg & Rapp 2013:55)

While searching through preliminary research on disability, I found a lot of articles discussing Ginsburg and Rapp's (2013) question, exploring the ways in which the discipline of anthropology could be beneficial to the study of disability. Ginsburg and Rapp (2020) argue that the discipline can contribute to exploring how public spaces or development in the context of the Global South include or exclude people with disability. In continuation, Hartblay (2020) suggest that anthropology can be a help to broaden the general view of people with disability - by centering the voices of people living with a disability themselves, a display of their own agency, might provide the reader with feeling less pity and more admiration towards people with disability. Ethnographic studies of people living with disability can serve as a critique of taken-for-granted norms in any culture in question (McDermott & Varenne 1995), opening the question of what a disability perspective might illuminate about our shared social world in terms of social or material exclusion and creative world-making.

While the past decade has witnessed a considerable increase in anthropological engagement with critical disability studies (Wool 2015, Dokumaci 2023, Kulick 2015), disability is still, as Ginsburg and Rapp argued in 2013, under-represented within anthropology today, particularly in contexts outside what gets called "the Global North.". The terminology *the Global North* is not a geographical reference but one referring to the relative power and wealth of a cluster of specific countries around the world, the same applies when the term *the Global South* is used in this paper (Braff & Nelson 2022). With my study, I seek to contribute to the integration of disability as a site of anthropological inquiry and theorization. Specifically, I draw upon the anthropological attention to everyday life experiences of people living with a disability, how people navigate everyday life with ‘a difference’, and exploring which social, economic, and political conditions contribute to their lived experiences. Within the body of research anthropologists have conducted on disability, the following themes in particular are most relevant to my study: discourse and labelling, disability within a Global South context, family and care, intersectionality, and finally mobilization and activism. These themes will briefly be discussed below, drawing upon the relevant literature.

Multiple anthropologists or other researchers navigating within the field of disability such as Schneider and Ingram (1993), Reno (2021), McCarthy (2021) and Hartblay (2020) have explored and discussed the discursive dimensions of disability, the power of wording used, the social construction of labelling/stigma, and perceptions of the word “disability,” and, by extension, of people living with disability. Schneider and Ingram (1993) illustrate how new labels through time have been introduced as an attempt to overturn negative stereotyping of disability but argue that unfortunately, stigma often infiltrates the new replacement term. Reno (2021) adds how we unconsciously use disability wording in common phrases when referring to failures or barriers, i.e., “blind to the possibility” (2021:143). Furthermore McCarthy (2021) argues that person-first-language is important to encourage the distinction between disability as a term of identity description versus something that a person carries or lives with i.e. instead of ‘she is disabled’, then ‘she has a disability’. Finally, Hartblay (2020) argues that due to social constructions in each society of what a ‘normal’ able-body looks like and is capable of, encountering a person who falls outside these norms may invoke pity, fear, repulsion, or anxieties– often subconsciously. The power of discursive framings in influencing emotional or social behaviors and reactions – both consciously and subconsciously – towards people with disability resonates with my own research findings. In Chapter 2, I explore how labelling can have direct impact on the everyday life experience of people with disability, their efforts to change how people speak about disability, but also how people with disability themselves sometimes reinforce constructed categories in the face of a lack of better terms, or because of the convenience of a common shared referent.

The body of research focusing on differences in the Global North and Global South in regard to the construction and experience of disability emphasizes two important considerations for researchers. Grech and Soldatic (2016) state that coming from the Global North, one needs to be aware of embedded power relations and knowledge production process in place. Stressing the importance of making space for learning and paying critical attention to local practices, material conditions, and epistemologies, which may differ significantly from those in the Global North (2016). This approach carves space for one's interlocutors to challenge dominant understandings of disability. Furthermore, in this body of research the question of whether disability as a category and lived experience can travel across socioeconomic, cultural, or political contexts has also been stated as important to keep in mind. Through my own research I have endeavored to learn from local practices, discourses and epistemologies and center the voices of people with disabilities in the ethnographic storytelling by exclusively working with interlocutors either with a disability themselves or their family members. Finally, through the paradoxes found in the interaction between local discursive framings and material conditions, I have tried to illustrate that more than one narrative can be true at the same time and show how the local ideas sometimes challenges the dominant understanding of disability and care (Mills & Davar 2016).

Research attending to disability in the Global South emphasizes the distributed role of family in care practices (Wickenden & Jean Elphick 2016, Grech 2015, Addlakha 2020). In her study on disability as being a family lived experience in the context of neoliberal India, Addlakha (2020:46) explores how care work by family members is carried out and how for people with disability in low-income countries caring from family members becomes a source of survival. Furthermore, Addlakha illustrates how, even though essential, this care work can both be oppressive or cause massive opportunity loss for the caregiver, but at the same time also be a source of fulfillment to the caregiver and the one cared for (2020:53). Finally, hospitals or institutions become a necessary and convenient resort for the person with disability and its family members (2020:50). In Chapter 3, I enter my findings into conversation with Addlakha's above statement in terms of disability being a family lived experience and how the care work of family members - even when it comes with a cost - becomes essential as a creative tool for navigating and surviving in their given society. I will furthermore draw from similar examples found by Wickenden & Jean Elphick (2016) in South Africa and Grech (2015) in Guatemala. In contrast to Addlakha's study, my interlocutors did not have hospital or institutions as a helping resort.

No social issue can stand alone and therefore research within disability studies also engages with critical work on intersectionality. The concept of intersectionality was coined by Crenshaw (1991) and is a theory of how and where different forms of power (and disregard) intersect and collide. These studies explore the importance of being aware of other structural, political, economic, and social factors as they interplay with disability. Eide and Ingstad (2011) mainly focus on the intersection between poverty and disability, while Grech (2015) extend this intersection exploring how poverty and disability influence the ability to mobilize politically and adding the factor of low political interest often found within the field of poverty and disability. Grech and Soldatic (2016) identify the most important intersectional factors important to consider when engaging with the Global South and disability as: gender, kinship, accessibility, class, rurality, and national location. All these factors, I will show, are worth considering when researching disability in the context of Pando, Bolivia. In Chapter 4, I will explore what I found as a gothic knot of factors intersecting, influencing, and creating disability, which are predominantly: poverty, lack of political interest or assistance, and infrastructural breakdown.

Within preliminary research concerning mobilization and activism in the context of disability, Kirakosyan's (2016) study focusing on the promotion of disability rights in Brazil argues that to improve the effectiveness of advocacy work, one needs to engage with a broader set of actors within the society in question. This collaboration with various actors in the surrounding community can help generate a deeper social change regarding the general negative or pitiful attitudes or perceptions towards people with disability. In my field site, a region where NGOs were not present to help fighting for disability rights to the same extent as in Kirakosyan's study, the aim of the pilot project was to mobilize on a voluntarily basis and educate people within the disability community themselves concerning their rights and abilities to generate both social and political changes. So ideally, as Kirakosyan suggests, the goal would be to engage the whole surrounding community in the fight for better rights and conditions for people with disabilities in the area. Still, at this point, I observed that the first step of importance was getting the people with disabilities themselves or their family members to mobilize in the various municipalities to fight for the common cause. In continuation of the idea of people with different types of disability joining to fight for a common cause de Beco (2021) points to the fact that even though the idea of a strong collective voice can be useful when advocating for rights and change, it also has its pitfalls. These pitfalls can include competing interests of member organization or individuals depending on their particular type of disability. During my study I found this issue to be prevalent. While my different interlocutors did not directly articulate an agenda to promote the interest of their category before others, they did express suspicion that the others beside themselves had this secret agenda. I elaborate on this paradox between collective action and competing interests further in Chapter 5.

From the preliminary research I discovered important theoretical and analytical tools to bring with me to my field site in Pando, Bolivia, which is considered under the term "the Global

South". Chief among these were the critical question of whether the category and experience of "disability" can travel and the necessity of prioritizing and learning from the local epistemologies (Grech & Soldatic 2016) that constitute it. Furthermore, I found that the above themes in the preliminary research— *discourse and labelling, disability within a Global South context, family and care, intersectionality, and finally mobilization and activism* —combined with my own findings legitimize my focus of research and sub-questions posed in terms of what needs to be included in order to grasp what is creating and affecting my interlocutor's everyday experiences of living with a disability.

Theoretical framework

In this section I will provide an overview of the theoretical framework I have chosen and found necessary for me to answer my overarching and sub-question based on my empirical findings.

As my aim with the paper is to center the voice of the people living with a disability, I needed a theoretical framework that allowed me to explore how people with disability perform agency instead of being passive bystanders of their own lives. I found Ginsburg and Rapp (2013, 2020) theoretical concept of 'disability world-making' to fulfill that aim. It turns the focus on how people with a disability creatively overcome the constant socioeconomic, moral/ethical, cultural, and political challenges internalized and experienced in everyday contexts, but often shaped by outside geopolitical processes (2020:7). Thereby moving the focus from a previous tendency of framing people with disability as "suffering objects" to rather focus on the creative challenges their faced difficulties might contribute to the local social life (Ginsburg&Rapp, 2020:7). In continuation Ginsburg and Rapp (2020) determine disability to be a relational category, providing an analytical tool to explore how this creative-worldmaking or disability worlds are being formed and influenced in the interaction between the local discursive framings of disability and the surrounding material conditions in the context of Cobija/Pando. In this paper I define discursive framings to include (what people say, social narratives, legislation, what NGO materials say, research concepts) and material conditions to refer to (what strategies and tactics are in place, interventions, materially built things).

As I found during my fieldwork, the creation of 'disability world' is a living process created and redesigned in the intersection between the local discursive framings and the surrounding material conditions. Reframing of labels, wording, definition of 'normativity' or changes in the material conditions can start the production of a new kind of disability world (2020:5). Facing new barriers or challenges to overcome and new innovating creative tools needing to be found or invented for the purpose. This focus on creative cultural production in terms of disability world-making can provide a knowledge of how "everyday life with difference" is experienced in an often exclusive local and global context (2020:5), therefore I find it useful to apply as exploring the everyday life experiences by people with disability is my focus of study.

As I found the problematic infrastructure, general material conditions and poverty as prominent catalysators for an even higher exclusion from participation or access of my interlocutors to meetings with the association, beneficial services, social activities or general communal participation, Rapp and Ginsburg's (2013) idea of an inclusive built environment as fundamental for a fully democratic society as useful to include in my analysis. They argue that societies, cities or institutions can systematically and socially 'dis-able' the people with disability even further if the public spaces or designed systems hinder their fully participation or access on a practical level (Ginsburg & Rapp 2020). Finally, Hartblay's (2020) concept of 'disability expertise' referring to that people with disability are 'not only users but also makers and designers of their own material-discursive world', I found useful to implement in terms of how my interlocutors tries to change and redesign the negative terminology surrounding disability. Thereby promoting empowerment and ableness on an everyday level. Another important factor influencing the everyday life of my interlocutors was family. My chosen theoretical frameworks for this will be explored below.

Based on her research conducted in China, Ma (2019) argues how family-focused formation of disability is found to be the norm rather than the exception in most of the Global South a useful analytical tool in terms of my own findings during fieldwork discovering that the lived experience of disability and family care was inextricable. According to Ma, 'family' should in these cases be viewed as a unit of survival. This could be explained by fewer (if any) external sociopolitical welfare structures providing help for people with disabilities than in "the Global North". One could say that in these cases disability bleeds, spreading and affecting not only the person with the disability but the entire family. Because I found family and their care work to be vital for the everyday life and survival for the people with disability within my field site, a theoretical lens to explore the effect on the family members was needed. I found that in Rapp and Ginsburg's (2001) concept of re-writing kinship.

Rapp and Ginsburg (2001) discuss how it is not only the person with disability, but also the person's family/next of kin, that needs to come to terms with being the family of a person with a disability. For any family, having a child with disability can cause a crisis to the normative nuclear and extended family idea (2001:536). This position and the need of helping their loved one can both affect their self-identity or physical and economic conditions. Using the United States as their point of discussion, Rapp and Ginsburg illustrate how disability entering a family can cause precarious situations for many parents already managing a tight household economy, in terms of balancing providing for the whole family, all the while completing one's family responsibility and taking care of the individuals requiring extra needs (2001:542). Furthermore, they discuss how families deal with having a family member with disability (publicly or privately) can reveal the whole community's point of view on people with disabilities (Rapp & Ginsburg 2001). Are they hidden away or seen as a burden? Or is it something one talks about and help each other dealing with the difficulties it might entail? These questions are useful in exploring how the families I encountered deal with having a family member with disability. It can tell us about the general point of view of the community, but also what consequences it can have for the person with disability if the outcome of re-writing kinship is either successful (embraced, respected, or helped on equal terms) or fails (burden, neglected, oppressive).

In sum, Rapp and Ginsburg's paper focuses on the re-writing of kinship regarding parents conceiving a child with disability. Navigating and getting through the immediate crisis this might cause to the local normative idea of what a family is. While this fits some of my interlocutor's position, I will extend the concept of re-writing kinship to include how people with a disability also need to re-write kinship when they create their own family, which does not either live up to the idea of a normative nuclear family. The same goes for parents acquiring a disability later in life, suddenly needing to re-write and re-think both their own self-identity and creatively find a way to continuously being a good parent and find a new way to provide for their children. Following Ma (2019), the family, as I will illustrate in my thesis, can be understood as a unit of survival and therefore a positive successful re-writing of kinship is of great importance to my interlocutors.

One of the general living conditions intersecting or affecting the everyday life experiences for the population in general, but especially for the people with disability in the context of Pando was poverty. Therefore, I found Eide and Ingstad (2011) theoretical framework concerning disability and poverty essential to apply in my research. In their book Eide and Ingstad (2011) attempt to detangle the complex relationship between disability and poverty. Focusing on low-income countries, their point of how the disabled perspective illustrate a condition of poverty within poverty, I found useful to describe or explain the local socioeconomic situation of my field site. Even in cases where the general society or population is struggling with poverty, lack of work, travel expenses, etcetera, people with disabilities are more vulnerable to these forces, keeping them in what Eide & Ingstad refer to as a 'vicious circle'. In general, they argue that for every poverty-related barrier found in a low-income country, a person with disability will be more vulnerable or worse off than a person without (2011:3). Furthermore, they stress the importance of exploring the social, political, and cultural processes linking disability and poverty to detangle the complex relationship between these two aspects, obtaining this knowledge by listening to the experiences and voices of the people with disabilities themselves (2011:225).

Extending the concept of poverty within poverty, given that Pando is one of the most isolated regions due to the lack of sufficient infrastructure, such as asphalt roads connecting it to the rest of the country, and being one of the 3 departments with the highest level of poverty (Wikipedia 2022), Pando Department could be labelled as a region of poverty within poverty, when referring to Bolivia in general. As I will illustrate in Chapter 4, the living conditions for people with disability in the department of Pando cannot be used to generalize in terms of living conditions for people with disability in Bolivia. Pando may be one of the most isolated and poorest places to live in terms of available resources in the whole of Bolivia, making the analytic of poverty within poverty all the more relevant when analyzing how experiences of disability intersect with social and material conditions of everyday life.

Furthermore, I found Eide and Ingstad (2011) concepts of 'the heroes of the everyday life' and 'social suffering' useful in my analysis. The first offers a focus on the strength, and not suffering, that people demonstrate when overcoming the hurdles faced while navigating in a society as both poor and living with disability. Secondly, the term 'social suffering' is interesting in that it removes the guilt or blame from the individual for being in their given situation, holding accountable outside forces like the political, ecological, and economic, which exists largely outside individuals' control. This emphasis on removing the responsibility for the suffering or difficulties experienced by the individual with disability embedded in the concept 'social suffering' is equal to the UN and national definition of Bolivia in terms of what constitutes a disability (Chapter 2). Removing the responsibility and blame from the individual, I found to be important in terms of empowerment and to generate an understanding of one's disability as only a limitation and that the many difficulties faced on the daily basis are only because the society is not built to include you. But a paradox emerged when the responsibility of changing this exclusive society is being placed back on the shoulders of these same people on a practical level. These interacting narratives occurring simultaneously and the paradoxes it sparks will be a general analytical lens used throughout this paper. One of these paradoxes is that I found both lack of political interest and at the same time the wish by my interlocutors to unite and political mobilize to generate changes for the better in their everyday lives. The theoretical framework found to shed light on this part of the analysis will be discussed below.

Firstly, Schneider and Ingram (1993) provide a useful theoretical lens to understand why the topic of disability often is forgotten or underprioritized in terms of political discussions, interest, and policymaking. They suggest two key motivations of elected officials. First, the production of public policies which can gain them reelection. Second, the public policies they produce addresses a widely acknowledged public problem (1993:335). Therefore, because people with disabilities are a part of the group with low voting percentage, the political interest in the area decreases. So, if the elected officials do not consider the problems for people with disabilities as widely acknowledged by the stronger target populations with a higher voting percentage, then they will not be a high priority (Schneider & Ingram,1993). In terms of my conducted fieldwork, I have not found an expressed importance from my interlocutors in terms of needing to make disability a widely acknowledged public problem to generate political and social conditional changes. This was a future goal, but staying realistic, my interlocutors found it important to firstly mobilize more people within the community and establish a better collaboration between the different categories of disability. So, the answer to become a priority is an organized and united disability community in confrontation with authorities, making them aware of the experienced problems in their everyday life and demanding, while also proposing, a solution.

To describe this need to unite and organize to fight for a common cause despite having different life conditions or types of disability, I will extend Cutajar & Adjoe's (2016) term: 'diversity within unity'. They use the phrase 'politics of diversity within unity' to refer to how scholars and activists must acknowledge the variety of identities amongst people with disability if a national and global mobilization should take place (Grech & Soldatic 2016: xxvi). Even though used in a different context, I found that it could be a useful metaphor in the case of my fieldwork as I will unfold and illustrate further in Chapter 5.

Finally, Rapp and Ginsburg (2001) refer to the importance of remembering that not everyone is able to 'rise to the occasion' as expected of them, depending on their socioeconomic circumstances. In this case, referring to the parents of children with disability, but I would argue that it can be used to describe the situation of both a person with a disability or family member to one. They argue that one can still find a discrepancy between the rhetoric of public inclusion and the daily battles still needing to be fought to ensure their availability in practice. The key point is that not everyone is able to or will fight these battles (2001:541). This, I will argue, is the same case in terms of what my interlocutors' experience in their situation. Especially the parents to a child with either an intellectual or psychological/mental disability. The expectation of them 'rising to the occasion' exists in the local kinship narrative, but both external circumstances and internal conflicts sometimes does not allow them to or at least makes it difficult.

Methodology

While interning with DPOD prior to conducting the research in this paper, I contacted one of its member organizations, The Danish Association of the Physically Disabled (DHF), to ask if it would be possible to connect with one of their projects or collaborations in Bolivia as a field site for this thesis. Even though the association in Denmark only focus on people with a physical disability, their projects in Bolivia focused on all types of disability. I connected with Eduardo at DHF's office in Cochabamba and determined the period for my fieldwork was going to be from the 8th of March – 1st of July 2023. As I only had three months to conduct my fieldwork, I chose to observe and participate in their new pilot project in the Department of Pando as a gateway to the people with disabilities in the area. This was the community I wished as my interlocutors in the thesis, as it was their personal stories and everyday life experience that I was most interested in. Given the time frame for conducting the fieldwork, Cobija seemed more manageable as a localized fieldsite, rather than travelling around Bolivia following the work of an association for one specific type of disability. Thereby Cobija became the main location for my participation observation and semi-structured interviews. Additionally, I was able to get to travel to 6 other municipalities in the region of Pando (Appendix 1, Map 2).

The research conducted for this paper would, quite practically, not have been possible without the access granted by gatekeepers. Being informed by Henry from DHF from the initial planning stages and based on my own prior experiences while travelling in the southern part of

Bolivia, the people of Cobija can be reserved and, in this case, suspicious of what I wanted from them or my purpose with the thesis. Furthermore, I found disability to be a vulnerable and personal topic for these people to discuss or open up about to a complete stranger due to the struggles or sometimes shame attached to having a disability or a family member with one in their society. Therefore, the following gatekeepers were valuable and necessary. **The main gatekeepers were Henry, Eduardo, Nancy from DHF** – without them I would not have access to anything, would have been harder work or maybe not even possible for me to just go and obtain this access. **The commission** – attending their meeting, evaluations and going to the municipalities, where I could meet the people living in more rural areas and obtain knowledge of the problems occurring there. Furthermore, the commission helped establishing a connection to the school of special education and La Defensoria del Pueblo (ombudsman). **Associations** – going to their events and thereby becoming familiar with the families attending and helped to become a familiar face by the entire disability community in Cobija. **Individuals engage in the disability community** – suggesting other people to talk to i.e. **Luisa –** people at Roberto Rojas were suspicious towards foreigners and raised the question 'What does she want here?' Therefore, easier with a person they know, who was able to vouch for me. **Jean** – home visit with the physiotherapist gave me access to families for brief talks, who were less mobile and not able to make their way to Miky Maia. **Michael** – introduced me to the whole area in Castañales for people with a visual disability.

Upon arrival, without me requesting it, Eduardo and his team constructed a schedule for my first 1.5 months, with everything planned from trips to the municipalities with the purpose of socializing the new proposed laws, to social events arranged by the different disability associations, to interviews with the different associations and institutions operating within the area of disability in Cobija/Pando. Initially, I was skeptical about the extent of this preparation, but I later found out that if it was not for this schedule, I would not have obtained half of the data I have now as with hindsight, it was hard to plan meetings with my interlocutors. By having this schedule created by the people helping them with the project, my interlocutors felt compelled to comply with the interviews, wanted to help me with everything I needed and trusted me enough to tell me about their perspectives. Even though events, trips or interviews were planned beforehand, over time of connecting with and meeting people through the commission or social activities, I found there was space and time for self-planned interviews, participation, and snowballing strategy. This led to invitations for me to various events, dinner at people's house, private birthday parties and introductions to other people living with disabilities.

My empirical data consist of my 3 months at the field site through participant observation, 23 semi-structured interviews (16 women, 17 men – see Appendix 2) with a duration of 1,5-2 hours each and innumerable informal conversations throughout the course of the three months.

Semi-structured interviews: As stated above I did 23 semi-structured interviews with the duration of 1,5-2 hours each. I was inspired by Stark's (2020) "open notebook", referring to the researcher not having determined the research questions on beforehand but can explore it as lived process. Thereby being open to new information and point of interest during the field study. I found this approach necessary because of the complexities, discoveries, and own conceptions of what is important changes as the fieldwork went along. On the fourth interview I had more or less the written themes, guiding translated questions and a Spanish wordlist – but I only used them to guide or continue a conversation when silences occurred. Because I continuously interacted with my interlocutors - especially the ones being a part of the commission or the same people often joining the events - when a 'moment of discovery' as Stark (2020) calls it occur, I could keep going back and ask my interlocutors about these discoveries in informal conversations. Making my field work a living process through everyday life interactions. Quickly observed the bringing a beverage and a snack was good costume so I always brought that for interviews. Always oral consent before I recorded the interview. Most of the interviews was one on one, but during drop by home visit it would often be with a family member, otherwise I had two group interviews – one with two people from association for people with and auditory disability and the other with 8 people from the association for people with a visual disability.

I choose not to do solo interviews with people with either intellectual or mental/psychological disabilities because I did not find it ethical. Firstly, because I did not find it possible to thoroughly explain to them what their answers would be used for and the majority of the people within these two groups, I encountered were either kids or young adults. Furthermore, the young adults with a mental or psychological disability were often affected by medication, so they were not completely present or had a hard time communicating their own thoughts or feelings. Therefore, I often interviewed their parents in their presence, so they were able to chip in if they felt like it. Because I found disability to be a lived family experience in Pando, I found their experiences and stories representative for their children living with the disability.

Participant observation: Living with an elderly woman with no attachment to the disability community, I was able to do participant observation of the local everyday life in general. On one hand, it could have been a plus to live with one of my interlocutors in one of the barrios for people with disability, but when I learned the dynamics and divisions amongst my interlocutors, I was keenly aware of dividing my time and attention amongst them and the events or people they would want me to meet. I realized that this approach would provide me with the most and biggest diversity in perspectives. Also, the most confusing one to choose because my findings therefore went in all directions, when you thought that a pattern was emerging. This is one of the reasons that I have ended up illustrating these paradoxes in my empirical/analysis chapters. It is my way of exemplifying that more than one narrative can exist at the same time. Therefore, I also saw it as the best decision to live on 'neutral' ground. I did live with one interlocutor in Roberto Rojas for 4 days and came back for visits, social activities, or interviews in the various barrios for people with disability i.e., Roberto Rojas, Arenas and Castañales to get a sense of the everyday life and to become a familiar face in the area (Appendix 1, Map 3). Furthermore, due to these dynamics and division I was also conscious of gathering information from equal amounts of interlocutors in each group - as much as it was possible. Finally, beside everyday participant observation – attending meetings, family event, visit the barrios (Appendix 2) I also participated in going to 6 municipalities, got a sense of the rural areas, and socializing the law/promoting uniting. Also provided me with firsthand experience with the difficulties of their infrastructure.

Finally, because I have done qualitative ethnographic fieldwork and Pando being one of the regions socioeconomical worse of in general and for people with disability, my findings cannot be used to generalize regarding the present situation or everyday life experiences for people with disability in Bolivia. Not even generally in Pando. It can shed light on my interlocutor's everyday life experiences and through this lens obtain an idea of the social and political complexities occurring during the duration of my field study. And because preliminary research (Rapp & Ginsburg 2020) has pointed towards a gap of the inclusion of localized knowledge, personal narratives and experiences centering the voice of the people with disability within the research field – I have chosen this method to approach my fieldwork.

Reflexivity and ethical dilemmas

A challenge I faced initially and throughout when interacting with new interlocutors and people in the disability community, either in Cobija or the other municipalities, was the question of positionality. Following the advice of Stark (2020), I found it important to be aware and reflect on how coming from different socio-economic backgrounds, my given entry point and foreign appearances could impact my positionality when entering the field. Because my entrance to the field was through the organization DHF, my interlocutors initially thought that DHF was paying for my trip, and I was there on their behalf with the end goal of reporting back to DHF about the course of the project. In reality, I paid all my expenses myself and did not even receive funding from Lund University or other funding pools. This gap between the reality and perception of my positionality by the people I was collaborating with was understandable considering the local power dynamics which sparked due to my entry point to the field site through the organization which oversaw the project.

Before every interview, when engaging with new people or attending events with numerous people, I found it of great importance to communicate that gap to establish the conditions under which I was there. Ethically, I did so as I wanted to clarify that I did not have any influence on the future of the project or other financial help in the future. Furthermore, I did it to ethically insure informed consent by the individual interlocutors and the general disability community (Stark 2020). Underlining the aim of the project and what their utterances might be used for. To me it was of great importance because due to the small-town gossip and jealousy jargon, I did not want any of my interlocutors to incriminate themselves. In terms of gathering data, communicating that gap helped create a safer, trustworthy, and honest space for my interlocutors to express themselves. I found that when they grasped the reality of my position and wish to learn from them and obtain an understanding of everyday life in Cobija/Pando based on their personal experiences and stories, they started sharing more detailed stories, even though it might make them emotional or appear vulnerable. While at first suspicious of why I found that interesting, being humble, communicating my goal and sharing my own experiences with people with disabilities in Denmark and knowledge of their abilities helped build up trust.

Another reflection of impact is my awareness of the underlining postcolonial power relations being sparked when entering the field as a tall foreign white woman. As the only foreigner in the area and the first to focus on social issues, I attracted attention everywhere I went. Being openly called or referred to as *gringa* (foreign), *flaca* (skinny) and *blanca* (white) on a daily basis. I even encountered one woman openly blurring it out with the comment “A rich foreigner wanting to learn about the poor people”, when entering a home asking if I could ask her son some questions about his disability. While it was hurtful, I understand where their distrust and stigmas were coming from, so it just made me work harder on appearing humbler, listening intensively, and helping with practical stuff during events, activities or even evacuation of people during the flood.

Furthermore, I tried to take advantage of the attention by using it to obtain new personal stories, access to new groups of people etc. Also, I used my appearance to give back in the sense of me showing up or taking an interest in their work is something they were using to promote their own cause. Because there is not any statistics being produced showing institutions or organizations work achievements, the only way for anyone to illustrate their achievements and hard work was through posting pictures of it on social media. Therefore, by taking pictures with my interlocutors (both privately and their press staff), being placed at the honor table at events so I can be seen on photos, was a way for them to increase attention and awareness from the general community or authorities. Illustrating 'look who is also interested in our project, a white foreigner'.

Doing fieldwork within an only Spanish speaking field site one impact and difficulty will occur – language barrier. Fortunately, I found it profitable in terms of shifting the power relation hierarchy enforced by my physical appearance and origins. Because even though I had studied and prepared my Spanish skills intensively the last 6 months up until entering the field, this area being so close to the Brazilian border had a mix with Portuguese and the locals talked fast and without endings. This caused some initial insecurities and problems with participation or understanding. Even though I quickly got used to the accent, something will always be lost in translation. On a positive side I found it to be profitable in other ways. When I sometimes became a laughingstock amongst my interlocutors because I did not understand a phrase or asking them to repeat or explain a specific word, that I did not understand, it helped shifting this power relation hierarchy, that was always present due to my appearance and home country.

The last ethical dilemma I found myself facing while writing this thesis was regarding representation in writing. I have felt a major responsibility for representing my interlocutors and their situation as truthfully as possible. It will always be subjective, but I have tried to balance my wish to not making them appear as suffering objects or primitive to the readers and on the other side not to romanticize their situation and depict the realities of the poverty level and poor conditions for people with disabilities in Pando. By using fitting photos for the different sections throughout, I hope to further the truthfulness of my representation, adding a visual layer to the written words. Lastly in terms of writing, at times in my empirical/analytical chapters, I will compare my findings to situations or practices in Denmark. I have chosen this to illustrate and discuss the differences, or similarities, in practices in a given situation. I did not feel like I have the authority or background knowledge to compare the instances with the general Global North ideas or practices, therefore I have used the knowledge and experiences I got concerning the situation in Denmark through my internship at Danish Disabilities Organizations.

Chapter 2: The constitution of ‘disability in Pando

In this chapter I will focus on what constitute disability as a relational category providing me with an analytical tool to explore how this creative-worldmaking or disability worlds are being formed and redesigned in the interaction between the local discursive framings of disability and the surrounding material conditions in the context of Cobija/Pando. The definition and discursive categories of disability, reframing of labels, wording, definition of ‘normativity’ or changes in the material conditions can start the production of a new kind of disability world. Therefore, the focus in this chapter is on the definition of disability and how it affects who is to blame for the disability (individual or the society), disability categories, the use of wording and negative terminology and how these are challenged with the aim of empowerment. All affecting the lived experience and access to mobilization by my interlocutors. As disability should be understood as a relational category, we must also grasp what ‘ability’ entails within the local discursive framing (Rapp & Ginsburg 2020). Therefore, this is where this chapter starts.

What is ‘disability’ vs ‘ability’?

According to the pamphlet made by the Defensoría del Pueblo with the purpose of creating awareness amongst the people with disability about their rights, they explain that disability is:

> ‘Is the result of the interaction between the person with deficiencies and the barriers faced due to the attitude and the environment that prevent their full and effective participation in the community and on equal terms with the rest of the people’
>
> *(Defensoria del Pueblo 2012)*

This follows the definition of disability made by the UN (2006). Thereby one removes the wrongfully or responsibility aspect from the individual person by lifting it up and making it a communal or societal problem emerged by the lack of inclusion. *The deficiencies* are defined as problems with a person's physiological, psychological, mental, or anatomical functions. These deficiencies will be further developed below in the section about the five categories. *The barriers* are defined as obstacles, hindrances or absences that limit or prevent the access, utilization, interaction, or enjoyment of any space, features/equipment, services or development of activities and the participation. Interestingly, this definition of barriers does not only include the build environment but also people's negative attitudes towards a person with deficiencies. In sum, according to this national definition, *people with disabilities* are therefore the people with long term or permanent deficiencies, that when interacting with various barriers are prevented to participate fully or effective in the society on equal terms with the rest of the people.

During my various interviews with interlocutors, I have found the common local answer to the question what a disability is to be slightly more practical or simpler in its definition, like Sofia stating: "*A disability is anything that prevents one from practically doing an act or participate in anything that everyone else can*". Giving me the example, that if you are not able to hold a pen in your right hand that would be a disability, but that does not remove your other abilities to do everything else. As she continued while laughing: "like learning how to hold a pen and write with your left hand". Another local discursive framing of disability was used by the commission members during meetings to try to promote empowerment and abilities amongst the attendees from the given municipality: *"it is not an illness but a limitation from doing a thing in the same way as others*" in line with Schneider and Ingram's (1993) notion of the attempt to positive relabel. Now returning to the opposing question, then what does ability entail according to my interlocutors here in Cobija/Pando?

Simply explained building on the above-mentioned examples and various statements made by my interlocutors, having the ability for something would then entail a person not facing any barriers in their everyday lives due to any functional problem. It is having the ability or possibility to do and outlive what you want. With this said, three points continue to emerge or are mentioned when talking about ability: family, education, and work. To be able to create your own family, to be able to study and get an education, to be able to work and provide for your family. These aspects seem to be the most important things to archive by my interlocutors to generate this lived experience of feeling perceived as able or capable by the local community. Evidence of the importance of these factors to be considered a respected part of the society - not only by people with disability but the general population - can be found when either talking about or being showed pictures of any given person's close ones. People would never state the names of the persons in the pictures, instead they would always start with their family relation to the person, closely followed by their occupation or current study. As a result, I know the relation, study, education, and occupation of all my interlocutor's family members, but rarely their name or any personal details.

In sum, from the perspective of my interlocutor's 'ability' defined in negation– when a person is not facing a barrier in a given situation - produced as a mirror to the disability following Rapp and Ginsburg's (2020) notion of a relational category. Furthermore, I found disability and ability to co-exist because the goal of my interlocutors was not to obtain full biological ability. The goal was to find a way that made one able to do anything you wanted to despite a 'difference' and to obtain the three socioeconomical necessities in the context of Pando - family, education, work - to get through the everyday life. In other words, the goal for any person here is being able to fulfill their dreams and to contribute and participate in your community on the same terms and level as anyone else. Being 'normal,' as some of my interlocutors would compare it to in lack of a better word. This term 'normal' and how my informants feel towards 'normality' will be the subject of discussion later in this chapter. Firstly, now that we have established the relationship and definition between disability/ability, we will now explore how the discursive disability categories are constituted.

The discursive categories of disability

In Bolivia there are general 5 state-defined main categories of disabilities. These discursive categories are replicated on a local level, becoming an organizing principle in terms of created associations and wording used by the individuals themselves, when describing their disability in Cobija/Pando. As I will illustrate throughout this paper the discursive framing and distinction between these disability categories, while interacting with the material conditions in the area influences the lived experience of my interlocutors. Your ability to mobilize, rights to access or which labelling/discrimination you experience often depends on what different strata of disability you belong to. Therefore, I have chosen to reproduce the state disability categories and use the terminology throughout the paper, because it is along these lines in which access to mobilization is determined for both the individual and their family members. These state-defined main categories are as follows translated from the Defensoria del Pueblo's document (2012):

1. *Physical* – this category includes everyone with a physical functional problem. Both the people who are born with it and the people later acquiring it as a consequence of ex. an accident or illness. This is the biggest category in terms of members.

2. *Visual* – this includes everyone with a visual limitation/problem. Thereby both people who were born completely blind, the one born with a disease worsening their vision with age, low visual vision, or people who lost their vision on one or both eyes because of an accident or illness etc.

3. *Auditory* – this includes everyone with an auditive limitation/problem. Thereby both people who are born deaf or people who can hear but not speak - in short everyone who needs sign language to communicate.

4. *Intellectual* – this category includes everyone with a decreased intellectual ability. Within this category two subcategory can be found, the ones that are neurodivergent and the people with Down Syndrome

5. *Mental or Psychic* – this category includes everyone experiencing a problem with their mental or psychological function. There are many different types within this category, but a main division would be 1) the people diagnosed with schizophrenia, depression, epilepsy, bipolar etc. 2) the people – mostly kids, because it was fairly new – diagnosed with autism.

   The main distinction made, when asking my interlocutors, between an intellectual disability and a psychic/mental one is that the latter can make the person's behavior change in an instant – unreliable – and can have aggressive tendencies. Thereby this is not the state but local-defined difference. An example is one of my interlocutors with one sister having an intellectual disability and the other one a psychic one (schizophrenia): "She, *referring to her sister with an intellectual disability sitting next to us,* are not harming and are able to work with cleaning places. She just needs help with mathematical stuff like her bills or sometimes one telling her to clean, do the gardening or else she might forget. My other sister living with my mom has schizophrenia and therefore she can suddenly shift from nice to aggressive and dangerous, something just suddenly changes in her brain. You see this scar? Once she cut me here with a knife. She can also run around the house screaming if she does not get her medicine.”.

6. *Multiple* – This is not seen as a category per say, but it includes everyone that has more than one type of disability ex. a child who is born/or acquired by illness or accident both an intellectual and physical functional problem, a person with Down Syndrome and autism etc.

The use of negative terminology and the empowerment in changing the discourses

Many of my interlocutors found the usage of the term ‘normal’ annoying, hurtful, or made them feel labelled as ‘not normal’ and differentiated from the common population. One of my young interlocutors with a visual disability even stated during a group interview: “I’m tired of my friends using that word – because look at me, I’m not missing anything, I’m a whole person that looks like them and can achieve the same things. I’m the same as them”. This statement follows the same as Wickenden and Elphick (2016) heard among their young interlocutors in South Asia and Uganda – this wish to be seen and judge as an individual person, not from the perspective of what they can or cannot do (2016:181). Interestingly in the above statement is though, that being whole was an important factor for her – so a person missing an arm is not normal in her perspective? Beside ‘normal’ the word I heard my informant disproof of the most, but still reproducing it every time making a comparison is ‘loco’, used to differentiate between a person with an intellectual and one with and physic/mental disability. As a counter perspective one of my informants with a disability himself and a son with autism, does not view to be referred to as the counterpart for ‘normal’ or the term itself as an issue. The importance for him is to teach his son that despite not being like everyone else, he is still able to do or achieve the same things.

Despite that most of my interlocutors still tend to use the term ‘normal’ or ‘loco’ themselves in comparisons with others in lack of a better word. I have still not heard the phrase ‘born without a disability’, but always ‘I was born normal’ or ‘I was not born this way’. My interlocutors are thereby reproducing the terminology that differentiate from the common population – despite their expressed wish to be seen as an ordinary person belonging and contributing to their community. With that said some attempts are being made to changing the negative terminology, because the wording and use of negative terminology affect their lived experience of having a disability. Activating feelings of hurt, anger, isolation and being stigmatized from the surrounding community (Wickenden & Elphick 2016).

These attempt to change the discursive framings from negative or stigmatizing to empowering was trying in many ways to employ McCarthy's (2021) person-first language. To divide the individual from the disability. They made posters hanging around the city illustrating 'good language' when interaction or referring to a person with disability. While this was a good start and the empowerment was felt grooving and spreading within the disability community, the fully disability expertise (Hartblay 2020), was still not evolved in terms of managing the negative terminology or stigmas following them. Why should we need to include disability in our naming of each other? As my interlocutor expressed: *"Or just call me by my name, Henry*". Which is true, why should he always experience people approaching him or referring to him as the one with the visual disability. Hopefully, the empowerment and changing of negative terminology can bear fruit and be an internalized empowerment, not having to feel the need to improve their worth to the outside world because of embedded stigmas following the label 'disability'.

In this chapter I have explored what constitutes disability and being a relational category (Rapp & Ginsburg), also what the local framing of ability was. Being mirrored, ability was main understood as navigating the word without any barriers, but also based on one' ability to obtain a family, work and education. Furthermore, I have shown that in the local discursive framing of disability and what causes it (influenced by the UN definition) the responsibility and blame in wording/definition and the struggles faced because of it, is removed from the individual onto an exclusive society. This rhetorical division of the individual and the disability worked for my interlocutors in terms of empowerment and feeling of self-worth even though they had a 'difference' compared to others. A paradox was found in that my interlocutors on the one hand, actively trying and putting a value in educating other people with disability, their family members and the surrounding society in the correct wording when speaking of disability. And at the same time, they themselves reinforced negative stereotyping terminology in their lack of better words, when making distinction either between two categories or people with/without a disability,

This changing of how one speaks about disability is important as it can also change people's perception of disability on a practical level as Rapp and Ginsburg (2020) argues in terms of the living process of disability world-making. Because even though my interlocutors creatively try to build up this disability expertise (Hartblay 2020) to not letting other people's opinions affect their everyday life experiences, I have also illustrated how the opinions and perceptions of others still becomes internalized. It still affects their everyday behavior like in the example of the interlocutor's energy put into proving or surprising others with their ability to obtain the high valued factors of education, work, and own family. But even though the rhetorical removal of the wrongfully/responsibility from the individual onto an exclusive society is admirable and ideal in terms of the lived experience of empowerment and self-image, I found that in the socioeconomic and political context of Pando this responsibility in practice was placed back onto the same individual due to the materiel conditions in place. You had to find a creative way of navigating through this exclusive public arena on an everyday basis even though it was not your own fault. As I will explore in the chapter below, in this challenging situation, family, becomes my interlocutor's choice of what Rapp & Ginsburg (2020) would refer to as creative tool or unit of survival to navigate the public sphere with a 'difference'. But as I will illustrate, if this responsibility of help and care are not accepted and the rewriting of the local normative ideas of how a family should look like, unfortunately this creative tool can end up problematize this navigation even further.

Chapter 3: Family and the responsibility of care

Laila and her daugther

"I would not be anything if it wasn't for my family."

York, director of CODEPEDIS and has a visual disability

In general, I found the families here to be quite close and dependent on each other. As one of my local friends said: “You also get children to help ‘make the difficult things easier”. Furthermore, the locals I engaged with found it surprising that I had moved so far away from my parents in Denmark and the fact that I did not talk with them every day while I was there. Like Grech (2015) in her study of disability and poverty in a Guatemalan context, this strong dependent family-dynamic was not surprising in a low-income country like Bolivia, where the external helping structures are lacking and the interest or ability by the politicians to change these conditions are low (ibid.). In the context of the department of Pando, I found, what I would define as ‘circle of care’ – parents caring for their children and vice versa - made possible through the establishment of one’s own family, was necessary for the everyday life of every citizen, but vital in terms of survival for a person living with a disability. This dependence of family members is even inscribed in the national disability legislation. When providing for a person with a disability, the family member has the same rights as the given person with the disability. An example: one cannot be fired from a job if you are providing for a person with disability. Because of the poverty level and lack of external support – not even being able to use hospitals or institutions as a resort like the interlocutors of Addlakha (2020) in India – the ability for my interlocutors with a disability and their family members to re-write the local kinship narrative and stepping up to the task becomes crucial for the survival and participation in the surrounding society.

In this chapter, I explore exactly that. I will illustrate how family is established as a unit of survival (Ma 2019) and as a person with disability’s main creative tool to navigate and participate in a public arena (Ginsburg & Rapp 2020). Like Ma, I found family to be constituted as the smallest economic and political unit (Ma 2019) found within the society, but at the same time the most important and highest ranked in terms of responsibility of care. Created by a local narrative of kinship, that places the responsibility for taking care of one’s child or family members above the government. Therefore, it becomes crucial to the everyday life experiences of the people with a disability to establish their own family and that the re-writing of the local normative idea of kinship (Ginsburg & Rapp 2001) and taking on the responsibility of care is successful. If these re-writings are not successful, one’s family can become the problem and oppressing factor instead of the solution to navigate the public sphere with ‘a difference’.

In a flyer made by the Defensoria del Pueblo compiling the most important rights for people with disability, the first law mentioned is – a person with disabilities has a right to construct a family. The reason for this one being the first one mentioned is that creating your own family is the most important thing to do: firstly, secure people to help you in the future, and secondly create the feeling of belonging, participating, and contributing to society at the same level as everyone else. The right for a person with disability to found a family is a part of the UN Disability Convention, (OHCHR, 2006) so it is not something unique for Bolivia, but stating it as the first important right for people to be aware of in the flyer, illustrates the importance of letting both the people with disabilities and the rest of the society know that it is not only a possibility but a right they have. Thereby contributing to a local discursive framework of people with a disability's ability to create their own family, which also becomes a necessity in order to navigate and not being further socially disabled by the material conditions surrounding them.

In general, family members were used as a mean of transportation. Bringing and picking up their loved ones from one place to another. This help was especially needed by the group of people with a physical or visual disability making them unable to navigate a mode of transportation, often a motorcycle, themselves. Sometimes it was the job of a cuisine or child to help their aunt or parent around, other times it was a spouse picking them up or bringing them to places at certain hours during the day. Beside transportation, family members could also be one's creative tool to get access to an education. York even achieved a doctoral in law with the help of his wife attending classes with him in the evening and taking notes. It was presented to me as a given thing to do because this is just what family do. No questions asked. This I observed on multiple occasions, for example during three out of the six trips to different municipalities. On these trips different children tacked along to help their parents out with any difficulties they might be faced with due to their disability. Either in terms of guiding them around or helping them carrying bags.

I would argue York is an example of a person with disability, who has successfully re-written the local framed normative family image and narrative. He acknowledges that he needs his wife's help in terms of transportation and earlier in life for an education, but despite of these obstacles he still describes them as equals and him being able to live up to the responsibility of care and being a good dad to his kids. Thereby, extending the theoretical tool of Rapp and Ginsburg (2001) to also cover the importance of the parent living with a disability to re-write kinship for the person to proudly feel like he belongs in the local discursive framing of what a good parent is, despite needing help due to surrounding material conditions. In continuation, a person with the disability's own family members can become the solution, or creative tool (ibid), to navigate in the public sphere with a 'difference'. Though only if they can re-write kinship image and thereby taking on the responsibility of care despite the extra struggles or sacrifices it might entail. This finding will be explored below.

Being the solution, taking on the responsibility of care

In the end everything reflects back on the family both if anything goes right or wrong. 'It is our responsibility to educate ourselves of our child's needs, to make sure their rights are fulfilled, taking care of them, and passing along good manners', a mom preached at an event the International Day of Autism awareness. So, taking on the responsibility of care as a family or parents means that you fulfill your responsibility of nurturing, providing, helping, caring, and teaching your kids the right manners or values. This is the general perspective in the community, but these responsibilities can become harder or more demanding to fulfil if your child or family member is born with a disability or obtain one later in life. A family becoming the solution and the creative tool for the people with disability to navigate and obtain the ability to participate in the daily life of the community is one that takes on this responsibility of care despite the extra material or social struggles it might entail.


Julia and her family living outside of Cobija. Her struggles to overcome the local barriers and provide the needed medicine for her daughter will be explored in Chapter 3

One important factor mentioned when it comes to being good parents for your kids, especially when it comes to having a family member with disability, is educating yourself in the person's rights and needs, but also using your platform to educate other family members or the people around you in their needs or most importantly their abilities despite their disability. My interlocutor Jorge, a young man in a wheelchair, and his mother found it important to stress the fact that even though he was in a wheelchair his intellectual abilities are intact and therefore he was of course able to continue his university education. Another example is a mother named Cecilia, who had a son with depression. She always felt the need to educate me on the fact that her son might be a slow learner in reading, but he was great at remembering the news stories, when asked to give her a recap during their multiple phone calls during her work hours when he was at home.

A family living up to their responsibility of care knows that their family members are able despite their disability. Given the correct support, they can achieve things and – often – being able to get an education, work, create a family and in the end contribute to the society. In the case of people with severe disabilities or in need of an amount of medicine that makes it impossible for them to contribute even in terms of finding creative solutions, a good family will still take care of them and acknowledge them as an individual human being with a heart and feelings. Stepping up to your responsibility as a parent also include providing your children or family member with the confidence to achieve what they want or tacking along if needed. For example, Cecilia who every evening went with her son to his classes because he did not have the confidence to attend alone or a mother to a boy with Down Syndrome participating in his classes in the morning to make sure he got the right help. These women both had jobs, because they needed to provide for the whole family on top of this.

Furthermore, this responsibility of educating yourself in your children's needs and abilities was obvious when it came to the parents of children with autism. During the event on the National Day of Autism awareness speeches were made concerning this. Because it is a new group and no educational offer has been made for these kids yet, a mom urged the others to step up and educate themselves in which educational and general structures their kids need to be able to interact and participate in the everyday life. The problem is that without educating themselves in what autism entails a lot of their children can have aggressive outbursts, and therefore some parents will be trapped in the house unable to bring along their children to work or other social events. During the event one mother said: ”Usually it is difficult for us to make events, because our kids are difficult at social events, some parents are not attending because their kid cannot behave in an outside setting, but we know there is more kids with autism in the community. We just need to get an educational offer, so people can get more out”.

Overall, I found the responsibility of care placed on the female members of the family, in accordance what Wickenden and Elphick (2016) and Addlakha (2020) exploring care work and disability in respectively South Asia, Uganda and India. Interestingly, in the case of autism and responsibility of care it was different. Here it is often boys being diagnosed with it because with girls the symptoms are often different and harder to spot. Therefore, a big responsibility or urge for the dads to educate themselves in their son's needs, because they must be the role model for their sons. One of my interlocutors named Martín, who himself had a physical disability, told me: “I thought, that I was going to die” referring to the day he found out his son had autism. But he stepped up and spent the isolation time during Covid to transform, as he said, his house to be better suited for his son's needs and educating himself in how to handle his outbursts and giving him the structures in the everyday life. Furthermore, his present wish is that more dads –I would argue this was a common goal for all my interlocutors - are more openly about their own or their child having a disability. People should not hide away in their houses but make their way into the public eye. This would help destigmatize any given type of disability and illustrating the abilities of people having them. I found that both my interlocutors and the general population I talked to, felt that in recent years this had changed for the better. Now people showed their faces and their disabilities more in public spaces, which helps destigmatize disability in the general population and make it less shameful for others to step forward into the public eye.

Even though the examples above is told by my interlocutors in a taken-for-granted way – one need to do what one can to help one's family – I still found it hard and taken a toll on the people involved. Having an already vulnerable economy, one might need to leave work and stay home or spending all your spare time with your child with a disability to take care of them. If you as a parent obtain a disability, you need creatively find any possible way to still create an income, so you continuously can provide for your family. An example could be Fredrico becoming an online advertiser and radio host or the mother ending up in a wheelchair after a motorcycle accident baking and selling cakes and bread from her house. The strength, difficulties and need for thinking in a creative way by people with different types of disability to create their one family will be elaborated further below. My experiences while doing observations of their everyday lives and through my interviews is that it takes a grand amount of strength, willpower, and patience to overcome the struggles and continuously re-write kinship stay and living up to the responsibility of care normally put on parents or other family members. You take a family in an area, where most people are struggling with getting by on a day-to-day basis and make them even more vulnerable and challenged if one parent or a child gets a disability. During my interviews with either parents as caretakers for a child with disability or a parent with one themselves the majority got tears in their eyes, when asked to describe how they got by or made it work/providing for their family on a day-to-day basis despite the extra challenges due to the disability. Many of them said they had days where they wanted to leave everything or give up and sit in the corner feeling sorry for themselves, but "Gracios a Dios" they continued having the strength, patience and willpower needed to help their loved ones and get through this with what they have got. This aspect of taking on the responsibility of care work, even though part of the local kinship narrative, can therefore also become an oppressing factor for the caretaker, as found amongst the Indian interlocutors of Addlakha (2020).

In continuation, some families do not overcome to re-write kinship ideas and thereby neglecting the responsibility of care and therefore becomes an additional oppressor or problem in the everyday life experience of the people with a disability.

Being the problem, neglecting the responsibility of care

Interestingly, I have not interviewed anyone associating themselves with being ‘a neglecting parent or family´ or at the least admit it to me and make themselves look bad or irresponsible. But on the other hand, I have heard enough anecdotes from UMADIS, CODEPEDIS, the federation, Defensoria and the school to believe they exist.

I have heard incidents by my interlocutors concerning either their families or kids around them during childhood, that has scared them or hurt their confidence. I will give two examples of how family members can affect a child with disability’s believe in themselves and their abilities to contribute to society and thereby the family become one of the problems instead of solution to navigate in a world that are not build for them. First example is concerning the president of the association for people with a visual disability in Cobija, Juan (53 years). His parents told him to his face, that he had an illness and not knowing any other person around him with a visual disability, he told me: “I felt like I was the only blind person in the world, all alone, didn’t think there existed anyone like me”. Furthermore, his dream later became studying anthropology at university, but again he was told: “Why would you like to study? You have an illness; you will not make it through”. So, he never got an education, but still involved himself in making the first library for people with visual disability in Cobija with over 200 books and pursue his interest in anthropology through online communities. Finally, even though his family caused him problems because of their lack of help or confidence in him, on the positive side he is the most independent person with a visual disability I met during my time in Cobija/Pando – walking by himself to most places, navigating through memory and smell – because he had to learn. There was no one else to help him.

Another example illustrates Wickenden and Elphick’s (2016) finding amongst youths with disability in South Asia and Uganda concerning these individual not just being excluded from social participation in the wider society, but also within their own family. Gabriel, the president of the association for people with an auditory disability in Pando. He explained during an interview that even though he learned sign language from an early age, his siblings for example did not educate themselves in it. Therefore, he often felt excluded from his group of siblings, not having a voice to be heard. Feeling excluded and unheard both at home and in the general society took a great toll on his self-confidence. This also explains why the sense of community within the group of people with auditory disability is strong and often a bit excluded from the general community. Within this group of people, they are understood, heard and able to communicate exactly what they mean by themselves – not needing to go through an interpreter like outside in the 'real world'. One can call it an alternative family.

During my stay in Cobija/Pando I have heard worse descriptions of family behavior than the ones above. I have not met anyone who had experienced any of this with their own family, but from institutions like UMADIS, CODEPEDIS or the Federation I heard of these cases and an explanation of the grand problem concerning families and a member with disability. Cases where parents are seeing these children or adults as a burden, which result in neglect, violence, or abandonment. In an already cramped economic situation, one can understand that either having a family member obtaining a disability or giving birth to a child with one can be considered a burden. 'Now we have to work even harder, and it is an area we are not familiar with', could be one of the explanations and the fact that these parents might not believe that their child is going to be able to contribute to the household economy – so why bother going that extra mile to help them. I have heard cases of parents not going to the doctor, when their child needed it because it was too far and too expensive compared to what difference it would make. Violence against children or adult family members was mentioned as a common thing. This might be out of shame or annoyance of the burden this person is causing them or the fact that they view them as less than a 'normal' person. The dad of Cecilia's son with depression is described by her to be shameful of his son and avoid spending time with him, helping them moneywise or does not bring his relatives by to visit him when they are in town.

The worst incident of abandonment by parents I heard of was a couple leaving their child with an intellectual disability on a bus towards Cobija alone in the hope she would disappear out of their lives. Again, it could have been an economic thing, only heard this story from the president of the Federation. The child was found and sent back to her parents, because they should not be able to escape their responsibilities as parents. Because of this incident a new law in the new departmental law proposal is aimed towards helping a child like her. It would allow authorities to question in a situation like this if it would be in the child's best interest to be given back to her parents. Usually, the children would be brought back, no questions asked, because a parent should learn how to live up to their responsibilities. Following in the same tread, I also visited the only orphanage in the city. This was not just for children with disability, but I met at least 2 children that knew me because I had previously met them at the special education school (Cobija B). The normal period spent here was not until a new family was found. The majority only stayed for 2-4 weeks until the social workers at the orphanage had talked to the parents and made sure that they were now ready to fulfill their responsibilities as parents. This was also a question of lack of resources to have the kids stay over longer periods of time. They were looking for more outside founding, but until then they 'did what they could with what they got'.

Finally, I found a small paradox in the descriptions of what a neglecting family in the disability community would look like. On the one hand, 'They are taking advantage of their kid's or family member's benefits or bonuses' was the most common one. Here they refer to the bonus of 250 bolivianos a month or receiving a house in one of the barrios by the government. The director at Cobija B explained that they would only see some parents that one time a year where a bonus was being handed out on school grounds and that some parents used this money for themselves and not their child as intended. On the other hand, some interlocutors pointed out to me that if it was not for the bonus less families would care and provide the needed help for their children with disabilities. So, if you keep the bonus and other possible benefits it opens the opportunity for parents or family members to take advantage of their close one with a disability, but if you remove the bonus, it might worsen the situation or make less families care in general because then there is no economic gain or help to obtain.

The examples above illustrate different ways in which families are neglecting their responsibilities of care because of the extra difficulties caused by their family member having a disability. According to my interlocutors working in the field of disability they argue it all comes down to educating or making the families aware of their children's or other family member's abilities despite having a disability. This also explains why the sensibilization project concerning people with disabilities is mainly directed towards the parents/families and not the general public. The problems the people with disabilities experiences in families neglecting their responsibilities ex. malnourishment, violence, being seen as a burden, abandonment, exclusion, or lack of support, could arguably be different if one could make the parents understand that if they helped their children now, they might be able to contribute to the household in the future. Like in the case of Rapp and Ginsburg's (2001) interlocutor in USA, it is an understandably hard task with an already tight economy, but showing examples of how it could be worth it and that your child might be able to gain independence, an education, a job, and their own family in the end might make it be worth the effort in the eyes of the parents. Finally, more awareness and less stigmatization being felt from the outside community concerning people with disabilities in general could help give the families struggling with the re-writing of kinship the courage and willingness to embrace having a family member with a disability despite the extra struggles and sacrifices it might entail.

The paradox regarding the dependency of family taking on the responsibility of care

The paradox of the tight, strong family bond and necessity to have one for helping with getting the everyday life running in the future being intimately interwoven with the realization or lack of trust or responsibility put on the government to fix it for you. A pride is put on providing and creating the best life for your family, but it can be challenged if either you get a child with a disability, wanting a family as a person with a disability or managing/upholding your responsibility as a parent or wife/husband if you suddenly obtain one. It is a slippery slope and causes a need for 're-writing' kinship image and narrative (Rapp & Ginsburg 2001).

Another paradox that comes with being dependent on a family you are born into or has created as a person with disability is that this family can either be the solution to the majority of the challenges you will be facing and helping build your confidence or cause even bigger problems in your everyday life causing you to be abandoned, violently abused, neglected, malnourished etc. because you are considered a burden in an already tight family economy and everyday fight for survival. How a family choose to re-write kinship or have the surplus in their everyday lives to live up to their responsibilities as parents created by the society can be game changing. In the end everything – good or bad – will always reflect on the parents and their responsibility.

Having a pride and local dominant understanding of this responsibility of family members helping each other and this hierarchy of respect to your parents and elders. Referring to places in the south, where they view it as people being more egoistic or less helpful because of the greater help given by the authorities. Mentioned if one of their children or general family are not helping them as they should according to the codex of family. But also, positive stuff is bragged about or mentioned – the education their children are taking, all the help they give them and the acknowledgement of ‘not being anything without my family’ – general narrative but even more true when it comes to people with disability, because they need more crucial and extended help to get through, or basically being able to participate or contribute to society. They are their tool for accessing the ‘real world’. Does not take away their own abilities or agencies for succeeding or wanting to do their part – but in this environment not built for them and lack of external help, their family members, and the technological development becomes their gatekeepers in obtaining the feeling of belonging and being a citizen like everyone else.

As I have illustrated in this chapter, sharing identical traits to Addlakha’s (2020) interlocutors’ worldview, the idea of care is viewed more as a responsibility and sign of respect than extraordinary care or costumes as an outsider might perceive it, based on my experiences in my own culture. I found that this general normative idea of kinship and carework interwoven in each other. It could stem from a lot of things – the general lack of care or help from the government, generating the narrative of ‘we are left alone and most care and help each other’, and therefore importance is placed on creating a network of help (only people you like/trusts, often sharing the same opinions with) or often this network just constituted of your own family (Many children being born – which generates great sizes families and therefore lot of contacts or network spread out).

Cannot be tracked back to the government but would argue it more stems from the religious ideology and survival tactic. Even though division and discrimination amongst the people in the barrios for people with disabilities, or everywhere else, everyone has someone or their own network to care for or helping each other. So, care can be tracked from amongst the nuclear family – barrio – small-town community – region and care for their country as well, but from my interlocutors’ point of view not the government. It is more the care and responsibility at the nuclear family level that can be tracked all the way up to national legislation and laws. This family independency and responsibility of caring for each other is also reflected in the normalization of people living together multiple generations under one roof. Beside the importance for the everyday life experience by the individual living with a disability for themselves and their families to successfully re-write kinship, other forms of power also intersect and shape this experience. These forms of power will be the focus of the following chapter.

Chapter 4: Intersectionality and the responsibility of change

During my fieldwork I continuously experienced a grand discrepancy between what my interlocutors had a financial or material right to by law due to their disability vs. what they in practice were given or had access to. Both sides of the discrepancy affected by the interplay of poverty, lack of political engagement or responsibility and infrastructural breakdown problems. As a result, these material conditions are intersecting and ratifying the everyday life experience of having a disability. Using Rapp & Ginsburg argument of the category disability being relational previous in this paper, I will now add the concept of intersectionality to expand upon this and argue that the lived experience of having one is multidimensional (Crenshaw 1991). While disability is one form of marginalization and political disenfranchisement, it also intersects with and is ratified by lack of political interest, poverty, and infrastructural problems. I found all these three factors constituting this gothic knot of intersectionality to be in play and hard to dissect from each other within the arena of access to help, a functional healthcare system, and specialized knowledge focusing on disability. An arena that has a vital impact on the lived experience for people with disability and a good illustration of how often having a right to something does not mean you have access to it, or it is available to you in practice.

By applying the concept 'social suffering' as a theoretical approach to view these conditions – poverty, lack of political interest, bad infrastructure - found intersecting with the experience of disability as something forced upon my interlocutors and therefore out of their control. Finally, I found that poverty, lack of political interest and infrastructural problems intersected and influenced the everyday life experience of most of the population living in Pando. Though based on my own findings and the argument of Eide & Ingstad (2011) the people with disability have a disadvantage from the get-go due to their disability. Needing to overcome greater hurdles or fighting to proof their worth due to the local framed stigmas or material conditions lead them to be more vulnerable in contact with the imposed conditions. Placing people with disability within this poverty within poverty position (2011).

In this chapter I will firstly, dissect the gothic knot. Exploring and providing an overview of the specific forms of power in play. Secondly, I have chosen to use the lack of specialized help as an arena to illustrate and explore this gothic knot constructed by these three factors and how it intersects with disability and thereby plays a part in shaping the everyday life experience of my interlocutors. I could have chosen other arenas to illustrate my point – educational options or work opportunities – but during my time in the field, I found the lack of specialized help to be the most pressing issue intersecting with my interlocutors lived experiences. In continuation, I will illustrate how the local idea of what constitutes good care or treatment challenges the dominant established ideas. At least if you compare it to the dominant ideas flourishing in Denmark.

Poverty

Bolivia is classified as a low-income country and Pando as one of the three poorest departments within the country. A statistic shows that 68,4% of the population in Pando is classified as being poor and 26,5% as being really poor. Furthermore, Pando is one of the most expensive departments to live in. This can be explained by the general production of everyday necessities or food being low in the region and therefore the need for importing food or basic supplies rises. Because the roads connecting Pando to the rest of Bolivia are of poor quality, "son feos/they are ugly", as my interlocutors would say, land transportation by truck is during rainy season next to impossible. Therefore, import by plane or through the asphalt road connecting Cobija to Brazil are the only options.

While poverty is a general problem throughout the region, individuals with disabilities require more money for transportation, helping equipment such as wheelchairs, crutches etc., medication, doctor visits, or therapy consultations and fewer educational opportunities or lower probability of getting or even being able to maintain a job compared to the people without a disability. Thereby proving Eide & Ingstad's (2011) notion that people with disability in low-income countries find themselves in poverty within poverty. Sometimes with the consequence of maintaining these people in this vicious circle, because living in poverty can cause their children to have less, living under bad hygienic conditions or because of lack of genetic understanding or specialized medical help increase the risk of passing their disabilities on to their children.

"No hay plata" ("There isn't money") was a common phrase either when one interlocutor was expressing her wish to travel somewhere, another expressing the fear of not being able to buy the medicine her son needed or another saying it to a boy passing by trying to sell soda. The need to generate money, and if a person did not have a job or maybe only one in the household did, led to this living on a day-to-day basis for getting food on the table approach. This approach to the everyday life and fear of not being able to provide for your family, might also be one of the reasons behind my interlocutors often having a practical or problem solution approach to my questions. As I mentioned in my methodology, I tried during my first interviews to ask them personal, reflective questions concerning how they felt about having a disability and what it did to their self-image, but I often got a weird look before they continued to explain what needed to change in the society to make a better future. Fighting to survive and provide, might not leave the time for a deep self-reflection.

In continuation, I found a common narrative circulating here in Pando, in and outside the disability community, that it is frowned upon if a person just sits in the corner waiting to receive 'the easy option', which was explained to being receiving help from the government without doing anything for it themselves. Two of my interlocutors, Juan and Maurice, even had a name for it 'Asistencialismos'. They explained that, in their opinion, citizens are not progressive enough in their way of thinking or approach to business – as they view the culture of people in Denmark to be – this was the reason for the communities stand still in terms of development. These two interlocutors wanted the people of Pando to think further ahead than the day tomorrow, because from their point of view people would not go to work the next day if they earned enough for two days the day before. Therefore, people in Pando might live in poverty within poverty, but the general mentality of placing the responsibility for change on the individual urges the members of the community to work for the wished changes and benefits in order to deserve receiving them. I would argue that a reason for this almost neoliberal common narrative and world view found amongst my interlocutors and friends outside of the disability community has to do with the region being in the opposition to the government and therefore having negative attitudes towards what they consider to be socialism. By doing everything in their power to make it work, using their network and getting the best out of their living circumstances, my interlocutors thereby illustrate a great amount of strength, which following Eide & Ingstad (2011) makes them these 'heroes of everyday life'. Even though I doubt that my interlocutors would perceive themselves as such, the majority would see it as their responsibility and a necessity in order to get by and taking care of their family. Being already in a vulnerable position as poor and living with a disability in a low-income country, another factor as Grech (2015) also found amongst her interlocutors in Guatemala shaped the everyday life experiences – the powerlessness felt amongst the people with disability due to the lack of political engagement and refusal of taking responsibility.

Lack of political engagement and responsibility

During my initial conversations with DHF and their staff located in Cochabamba, it was explained that in Bolivia it was generally impossible to change anything on a national level if you did not represent the same political colors as the political party in charge of the government. That was the reason for DHF's pilot project having the aim to better the laws for people with disability on a departmental level instead of a national one. Since 2006 the political party in government has been the left-wing MAS or Movement for Socialism – Political Instrument for the Sovereignty of the Peoples (Wikipedia 2023b). The problem in terms of Pando is that the governor of the department and the mayor in Cobija are a part of the opposition party to the government. As my interlocutor working for the Defensoria del Pueblo told me, this indicates that the government only help with the minimum they are required to by legislation because they do not need the votes from this region to stay in parliament. This could also explain the negative attitude against socialism found amongst my interlocuters and the general population in the region. A general distrust caused by a great corruption within authorities and the lack of living up to their responsibilities or implementing laws on a practical level, continues to influence my interlocutors' attitude towards general local authorities and not just in terms of the government.

The director of the school for special education and the worker from the Defensoria del Pueblo explained to me that compared to the surrounding countries, Bolivia has some of the best laws and legislation when it comes to people with disability, however in terms of implementation and general living conditions, Bolivia is still worse off than its neighbors. This is often caused by politician's lack of interest in the area of disability, and lack of resources to implement their rights in practice. Or as argued by Grech (2015) based on her findings concerning the Guatemalan government's engagement with disability, a general lack of interest, training, and refusal to engage can be found amongst politicians regarding the area of disability and poverty (2015:221). This is not where the votes are (Schneider & Ingram 1993). Other than the example of the governor of Pando not using his platform to promote better conditions for people with disabilities, despite having one himself—only one mayor out of the six municipalities meetings I attended found the time to show up and engage in discussions with the citizens with a disability in his municipality. The others had more important meetings the day of our visits, even though the mayors were informed that their participation was one of the aims for socializing the laws with their community, as a means of promoting future collaboration between the local group of people with disabilities and the local authorities. Several of my interlocutors in Cobija also expressed their disappointment with the city's mayor who almost never participated in events or showed her face at the rehabilitation center Miky Maia.

The school of special education, other institutions working within the area or my local interlocutors with disability or family members to one, had come to the realization that external funding from international organizations or visiting foreigners were effective sources to instigate change or to make desired projects a reality – not the public authorities. This realization was also made based on the general few public resources being available at the moment of my visit. The mayor had taken over a grant debt and my interlocutor, Josef, working as director of the social office in the municipality of Cobija had not been compensated since November 2022. He was not the only public employee in that situation. Interestingly, he looked down upon other individuals quitting their jobs on this account and who did not continue working as he did. As he said: “We still need to keep the wheels of society rolling, they just want to receive and not give”. This realistic idea of what a person with disability could ask for from the authorities shined through in terms of money cannot be an excuse for not completing or arranging events or launching projects for the disability community – then one should just activate their network and make it happen together. Even though the general feeling was that the authorities were not doing enough, the belief that this would change soon was not apparent. The local consensus was that you must create and fight for the changes you want to see happening for yourself or your family. One positive outcome is the increase attention by the municipality of Cobija to implement and construct accessibility ramps around in the city center during recent years, though many were being constructed too steep for a wheelchair to use it on a practical level or in obscure places (*see picture*). This leaves us to the last important factor to consider in the gothic knot intersecting and shaping the lived experience of disability.

Infrastructure and distances

Emilio and his mom in their house in Arenas. Illustrating the difficult environment and his mode of transportation

To paint a picture of the infrastructural problems in Pando, one can use the wording expressed by all my interlocutors every time the roads are being brought up. That is most of the roads in Pando being 'terrible and ugly'. If you move a bit from the main roads of Cobija, most roads are like the orange clay road on the front page. This makes getting from A to B more difficult and time consuming especially if you, due to your disability, needed help from a family member to get around. Furthermore, due to the lack of asphalt roads everyone was immobile if the rain started to poor down. You could find different sizes of buses travels between the 15 different municipalities, but the options of public transport within a city like Cobija are few and far between. Generally, transportation is expensive and therefore only done when necessary. In reviewing the map located in the appendix, participating in a social event, association meeting or taking advantage of the free treatment available at Miky Maia in the city center, may cost a person living in one of the barrios up to 30 bolivianos back and forth by motorcycle taxi. This equates to three proper meals. Elaborated by my interlocutor, director of Miky Maia, Biviana: "We often see that it is the people with the resources that can get or take advantage of the help or services available at Miky Maia, the others cannot afford or are able to transport themselves there". Therefore, the unevenness can intensify, and the isolation and lack of access to help play a part in worsening the situation of the less fortunate living in the barrios or can be experienced in the municipalities placed far away from Cobija as well. This echoes what Ginsburg and Rapp (2013) frame as "socially disabling" in that in this case it is not just the disability of my interlocutors, but the infrastructure and poverty that are preventing them even further from participating or taking advantage of given benefits.

This infrastructural problem causes a bigger problem for the people with a disability living in the rural areas far from Cobija. Because Cobija is the only place with a CODEPEDIS office in the Pando Department, and the approach for acquiring the needed ID card or making request for other types of help is analogue and includes paperwork, many people must travel long distances to physically sign an important document in order to receive a specific service or monetary benefit. But the issue is not just for the people to spent money to travel to Cobija, it can also be seen in terms of attracting needed specialized help like a translator, psychologist, or social worker to the rural areas. As explained to me during a meeting in the municipality of Filadelfia: “We are not able to pay more than 6000 a month and no one wants to come live here far away from the city for that little”. So, using Filadelfia as an example 8 people with an auditory disability were living in this huge municipality, but not one translator was available to them.

Finally, due to the inadequate infrastructure compared to other departments in Bolivia, life in Pando comes to a standstill if it starts to rain. In Pando the weather, especially the rain, controls people’s ability to move around. As an example, while driving to Santa Rosa (Appendix, Map 2) it took us four hours to get there, but seven to get back because rain had fallen in the meantime, and it turned the road into soap. Throughout my field work, I even experienced the low part of the city being flooded, where we had to sail around in a boat helping people to evacuate. The whole city was at a standstill for a week afterwards because all the stadiums, university buildings and public workers were occupied to help to provide for the people without a roof over their head.

As a national attempt to minimize the living expenses for a person with a serious or very serious disability, these people are by law entitled to 50% discount of public transport. 25% of if a person has a disability in the ‘less serious category. Even though it is a start, transportation is still highly expensive, and does not include motorcycle taxis, which is the most common/if not only public transport within the city. Another improvement that has been made for compensating for the long distances, is a school bus for the children with disabilities, driving around the Barrios picking them up and returning them afterwards. Speaking with the teachers at Cobija B, I understood that before many students might not show up to school because it was too expensive for the parents to send them every day or less of a priority for them.

In this section I have briefly discussed and exemplified the three main factors intersecting, influencing, and creating disability in Cobija/Pando, which in reality is tight together in a gothic knot. This makes it impossible to dissect which factor is the dominant one or which one should be solved first in order to generate the most change. Furthermore, I have shown how two narratives circle within the local context at the same time. One, blaming the political authorities for their community’s socioeconomic state and the lack of interest in fulfilling their responsibility towards the people with disabilities. Another, acknowledging that the political authorities do not have the interest, time, or financial resources to do everything, thereby placing the responsibility of generating change and improvement on the individual to either make use of their personal network or making the authorities aware of your needs or rights. Within one arena – the lack of help, healthcare, and specialized knowledge – I found these forms of power i.e., poverty, the lack of political interest, and infrastructure intersecting, influencing, and creating disability. Furthermore, within this arena the two narratives also interplay. Shifting from the legislation right to have access to the necessary medicine or healthcare services to the complications for people to obtain or access these rights and services in practice due to their socioeconomical, geographical and political circumstances. This arena will be unfolded below.

Lack of help, healthcare, and specialized knowledge (doctors, neurologist, translators, psychologist, medicine, institutions etc.)


A mother receiving home physiotherapy because of her inability to reach Miki Maia. Does not have the money for an improvement operation.

One of the most mentioned social conditions affecting and intersection with my interlocutors' experiences of everyday life with a disability was the lack of help, healthcare, and specialized knowledge. An example of this could be how in general in Bolivia the possibility for scanning for possible disabilities during pregnancies is not an option. That also causes more people to be born with disability than other places. And because, especially in Pando, but in general there is a lack of specialists or people specialized in different areas (neurology, psychiatry etc.). A disability is often firstly detected later maybe not before the child is 5 years old. Once more poverty intersects in terms of families needing to travel far either to La Paz, Cochabamba, or Santa Cruz to get their child diagnosed. This was a general thing, if you got critically ill in Pando, you had to travel to the same distant cities because the hospitals in Pando are not equipped to deal with this. For people living in Cobija some might travel to a specialized hospital in Brazil, as it is closer and easier. Furthermore, a lot of people have obtained their disability later in life either because of an accident or diseases like polio, meningitis etc. Diseases where there are vaccinations but either not at a possibility here or once more an issue of money. One of my male interlocutors with a physical disability working as a radio host had gotten polio in his twenties and therefore lost his ability to walk. In continuation, Eide and Ingstad (2015) point towards how poverty intersect with disability in terms of medical care. As they have found poverty can cause people to not be able to reach the hospital in time or unable to afford available improvement treatment. This was unfortunately the case of a mother I briefly visited in her home, stuck in a wheelchair after an accident, because she was not able to afford an operation that could improve her condition.

Another issue regarding lack of resources and specialized help is the fact that there is no psychiatrist found in the whole department of Pando. Only one working privately for a company. Furthermore, a significant issue is lack of the medication needed for the people with a psychic or mental disability. When meeting Julia at her house, she was equally relaxed and in tears at the same time. Julia had just come from a meeting in town with the health department concerning the issue of acquiring a psychiatrist and the needed medication for her daughter with schizophrenia. Earlier on she had been promised these things by the mayor, but today the health department had told her these things where impossible to complete. There were no resources for it. The issue with the psychiatrist and medication was as following.

In Cobija or Pando is not an attractive neighborhood to move to because the living expenses are so high compared to the salary the authorities here were able to pay. So why should a professional move to an isolated and rural area like Pando, where the living expenses are higher than living in the big cities and the pay is worse. In terms of the acquired medication the reasons were more blurry but bottom line, as I understood it, the travel time for the medication to arrive was long and the authorities was not aware of the importance of these types of medication even though the problem was not a new one. Basically, a person with depression, bipolar or schizophrenia all classified as psychic/mental disabilities needs three different types of medication (clonazepam, carbamazepine, risperidone) to stay 'controlled' or insure no violent outburst against their surroundings. Normally only one of these three types of medication were available which caused insecurity and fear for the family and parents. Without the medication, the surrounding family did not know what their child or family member might do of harm to them or themselves.

When I met Julia, she was in tears because the night of my visit her daughter with schizophrenia's medicine would run out and she had not been able to acquire new ones. "What do I do tonight when we do not have more of them?" she cried. The uncertainty of what would then happen was tearing her apart. Furthermore, if her daughter did not get her necessary medicine to make her stay calm and 'controlled', Julia would not be able to leave the house or work. Luckily, because she reached out to her network within Miky Maia, I know from the Defensoria del Pueblo's Facebook post, that they helped her find a temporary medical solution the next day. This is an everyday example of how one of my interlocutors need to use resources for a short-term patchwork – in this case medication for her daughter – but in the absence of longer-term sustainable and reliable solutions, which can be hard to generate because of the material conditions of poverty, lack of political engagement and infrastructure breakdown. This creative work is ongoing and must be continually performed to circumnavigate resource shortage or other everyday hurdles needed to be overcome (Rapp & Ginsburg 2020).

The concept of medicating individuals with mental or psychological disabilities so they are under control makes the everyday life more flexible for the caretakers, as my interlocutors expressed it. This notion of keeping a person under control with the use of medication could seem unethical coming from a country where the options of treatment for these psychological or mental disabilities are advancing and people can often live a decent life with the illness. Or at least it was hard to experience people being so drugged that you could feel the presence of the person behind an intense and at times unsettling stare. Of course, in an ideal and resource-rich world, alternative and more individual options should be possible, but given the circumstances in Pando this would be unrealistic to expect in the nearest future. The best possible solution, as my interlocutors framed it, would be having the needed medicine in order to keep family members with a mental or psychological disability 'controlled', so the rest of the family have the opportunity to leave the house and work for a better future or survival for their family. Also, when asked if it is just because the right treatment, institutions or specialized help options are lacking, the mother and a sister to a person with schizophrenia replied – "Well it has been said that it would be best for them to stay at home".

As a final example of the impact of missing help from external structures or specialized knowledge is the lack of institutional options providing care or taking people with a disability in when their parents pass away and if these people are not able to take care of themselves. In similarity to Grech (2015) and Addlakha (2020), I found a deeply embedded generational anxieties concerning the future of livelihood for their children, when interviewing parents. This fear was the one causing the most tears and emotional responses every time it was brought up. The fact that there are no institutions able to take over the responsibility of care after them, provides them with a permanent fear and uncertainty. As one of my informants to a child in his late twenties with depression: “No one cares as must or on the same level for him as me”. For these reasons a lot of my informants with a child with disability took practical approach in terms of education, focusing on how I can help them to be independent or at least make their own money after I am gone. Finally, this is also an example, as the one above, on how the perception of the right care or treatment in ex. Denmark is challenged by the locals here.

During my final presentation for the commission and other interlocutors wanting to join I presented an example of how authorities in Denmark tries to remove this generational anxiety by telling them about the houses and workplaces focusing on helping people with Down Syndrome live independently with other’s having the same or similar difficulties. Afterwards I experience an interest and positive response on the idea of starting a café or restaurant specializing in having workers with disability and an institution providing help to their child after their parents passed away. That would remove the fear and concerns concerning the future from their shoulders. The part of the established institutions in Denmark that confused them was: “Why should parents place their child there even before they have passed away?”.

This family dependency and responsibility of caring for each other is also reflected in firstly the normalization of people living together multiple generations but also in the idea of what providing good care is or when speaking of people with disability which approach is the best to improve the life of these people. The answers by my informant I found to challenge the ‘Danish’ beliefs of the right treatment of a person with certain disabilities might be, seeing other treatments more plausible or providing their family members with better care (Mills & Davar 2016). In general, I found the strain of thought to be: Why hire help when you have family? Always family members paid to drive or pick them up places, writing notes for them during class, helping them while travelling etc. In conclusion, my interlocutors did not see the reason for getting someone from the ‘outside’ to do it.

So even though the examples above could also be argued from a ‘Global North’ point of view to be more examples of a population coping with the lack of external help or interest from their own government, it could also be seen as a worldview where the best thing you can hope for/create for yourself or your child with a disability is the possibility of being cared for by family members in your home. Where in contrast, in Denmark at least, it can often be seen as the best option for your child or for your surroundings to be hospitalized or sending your children with disabilities/or if you have a disability yourself move to a facility where they are encouraged and provided with the help needed to live an independent life without their parents or other family members. Where people with disabilities in Denmark will do everything to not become a burden for their surroundings and therefore seek to reach independence or at least external helpers (a way of showing care to their loved ones by not making their lives more difficult), in Pando people take it for granted that their family members help them with the difficulties they face in exchange for the other stuff or roles they fulfill in the household. Though some feelings of being a burden can still be detected when talking to some interlocutors, living and helping each other across multiple generations under one roof is more a given than a rarity. Especially for people with disability.

In the end: 'No simplemente tienen derechos, pero también deberes'

This phrase encapsulates what I have tried to illustrate in this section. "You do not only have rights, but also duties", this was repeated during the socialization of the new wished legislation concerning disability, when presented around the different municipalities. Here the 'duties' by the people with disability even had its own section in this law proposal. Explored in different intersectional iterations above, the theme of the government or authority's responsibility vs. the citizen having a duty to do something about their own situation – at least if they want to obtain respect from others. A common outspoken local narrative, and not just heard within the disability community, was: 'People are just lazy and want the easy option. Many people here just want to receive, receive, receive but not give anything back or work for it'. This narrative could be argued to be seated in a neoliberal way of thinking and corresponds well with the general local negative attitudes towards socialism and the government ruling of the de Mas party. So once again, we are faced with a paradox where two narratives operate at the same time, interwoven in one another and where one does not exclude the other.

On the one hand they have this general neoliberal way of thinking. The idea that people must work and make themselves deserve the things they receive, creating their own happiness and fight to obtain anything, contribute, work for it and not just sit and wait around to receive benefits or a job falling in your lab. On a positive note, this can help empower a person and by giving this responsibility to either the person with disability or a family member to one, the society also provide them with an opportunity to enact agency and to illustrate that they are not just these ‘suffering objects’ as the stigma often suggests. General laziness, selfishness or just waiting to receive governmental help or ‘the easy solution’ is looked down upon, so fighting to be able to provide for your family or showing surplus by also contributing to the general society illustrates strength and help build up respect by the surrounding community.

One the other hand, one could argue that this neoliberal way of thinking - placing the burden of change on the individual or ones family - is intimately interwoven with a realization of the government is never going to help or will forget them on purpose to safe the money (living from people’s unawareness of their rights or possibility for help), so therefore this is the only way to be heard and change their way of life. As I have illustrated in this chapter it is not because they do not blame the lack of specialized help, resources, medicine, bad infrastructure, missing of the bonus etc. on the authorities, but all demands or wish for the political authorities to step up and live up to their responsibilities in terms of enforcing and implementing the laws or having an interest in including or better the lives of people with disability, will always be followed by a critic if the demands of the people are not realistic. You cannot ask them for anything unrealistically, like a lot more money for example, but a pride is put in ‘doing what you can with what you have’, so an institution, association or individual person should not complain about lacking resources or money or use it as an excuse to not complete or create events or changes for the better in your own lives. Then it is up to you to use your network and create this change for yourself – plan a social event or activity, create your job, make education possible for you or in some way find a way to provide for yourself and family. As a phrase often used by my interlocutors to describe most of the society, which they find lazy: “La gente puede, solo no quiere” (People can, only they do not want to).

Though this should not be used as an excuse (even though one could fear it) for authorities to not contribute with more help in all areas i.e., better infrastructure and public transport, making the sector a greater priority overall, all the social conditions and sectoral problems they face – what Eide and Ingstad (2011) would refer to as examples of social suffering. I find it against my interlocutors will or they would hate me for portraying them as just suffering and poor creatures living in a primitive society. Because this is not the case, even though you do hear people mentioning that they are poor or suffering. Especially, family members to or people with psychological or mental disabilities because these people are during my time in Pando the worse of in terms of medicine and available help. But in most situations, you will still hear them in the next sentence mention: “…but we are happy”, “… but we will fight to get the authorities to provide us with the needed medicine” or “… but we are doing our best with what we got.”. Thereby, even though the responsibility for the suffering or difficulties my interlocutors' experience in their everyday life would be removed by labelling these conditions as social suffering and placing the responsibility on an exclusive society, on a practical level the responsibility still lies on the shoulders of the people with disability or their family.

So, you end up with this paradox of what is creating or maintaining them in this vicious circle of social suffering – poverty, lack of political engagement and responsibility, problematic infrastructure, lack of specialized help – is also what is creating or sparking this pride and respect in every person fighting for the changes they want to happen. Thereby, illustrating strength, agency and gaining respect for not being lazy and waiting to receive things from others. Even though it seems positive and great for the spirit of the general population, in the case of disability the responsibility for creating and fighting for these changes is also laid on the shoulders of the people or their families - even though definitely in possession of an enormous amount of strength and patience – also argued to be one of the most vulnerable groups in the society (Eide & Ingstad 2011). Illustrating the conflicting interplay between having a discursive manifested legal right to something does not mean you have access to it, or it is available to you in practice due to the local material conditions. Plus, while the blame, guilt, and responsibility for changing these conditions might in wording be placed on an exclusive society by labelling it 'social suffering', the responsibility is in reality placed on the shoulders of the people living in poverty within poverty (Ibid). It might be the realistic view on what will create the most changes and better the everyday lives of people with disabilities, but because of the current socioeconomic conditions some people might not have the opportunity or surplus to take up this fight for change (Ginsburg & Rapp 2001). The need to unite and organize into one common voice in order to generate positive changes and the challenges people within each category of disability might face due to the lived circumstances will be explored in the next chapter.

Chapter 5: The fight to change things for the better

- values (collaboration) vs. practices (internal conflicts)

"We need to unite and organize for us to have the strength to knock down the doors to the authorities. They are not just going to listen to one individual. You cannot just fight for your own type of disability, but we need to fight for all types of disabilities in a united voice."

The president of the Federation during a meeting in one of the municipalities.

"We are a land of discriminators."

The director of UMADIS, said with a smile but a serious undertone during an interview.

As illustrated above the realization by the disability community in the context of Pando regarding the necessity to unite is grounded in this lack of political engagement and fulfillment of responsibility for its citizens with disability (Grech 2015) as illustrated above. Especially in a setting like Pando being in the opposition of the seated government. Tired of the promises without implementation or lack of general political engagement with the pressing issues for people with disability, the only option was to unite and together knock down the door to the politician's attention. As Ma phrase it on behalf of her interlocuter with the same realization in the context of China: "They demand the state to be a proper parent" (Ma 2019). Even though this needed collaboration is outspoken and wished for by every single one of my interlocutors - a new paradox or difficulty becomes apparent on a practical level. A categorized or personal difficulty of grasping or come to terms with the diversity that needs to be contained within the common unity.

A local narrative of disbelief in other people's intentions for the common good or 'look of distrust' is flourishing within the disability community. So where does this disbelief in other people's intentions for the common good or 'look of distrust' stem from? I would argue that this 'look of distrust' found in Cobija/Pando towards people not within the same network or shared opinions could stem from the national division in which political colors you have. The people of Pando, being in the opposition and therefore neglected in terms of help from the government feels overlooked and forgotten. They have compacted this feeling of injustice and division into the local phrase 'Todo es Político/Everything is political' – reproducing this distrust in other people's intentions you do not know or being sure of injustice is at play when someone achieve or receive something that you did not but wanted. This phrase and belief system can be found outplayed and reproduced within the disability community as well. And the main area wherein this disbelief in other people's intentions for the common good can be found amongst my interlocutors is when it comes to collaboration or giving a powerful position to someone. Thereby, illustrating that my interlocutors believe de Beco's (2021) notion of every disability category or association always has a willingness or focus to fight a bit harder for promoting or achieving better conditions for their own first. Additionally, tensions and further difficulties to obtain the goal of promoting collaboration between the diversities within the ideal political active unity (Cutajar & Adjoe), can be understood by the difference in access to political mobilization amongst the various constructed disability categories. Differences caused by an interplay between the local discursive framings of disability, kinship responsibilities, and the material conditions including the build environment, access to a translator, infrastructure, and available treatment options.

Therefore, to further grasp how collaboration being this idealized vision of harmony and change can become a social messy affair in practice, one need to understand the diverse groups needing to be gathered within this unity and how the local framed discourses and material conditions affect their access to mobilize differently. Furthermore, how these differences in access can cause tension and inequality between the constructed categories. In the section below exploring these differences found in terms of mobilization, I have grouped physical with visual and intellectual with psychic/mental disability, because I find them to face some of the similar advantages and disadvantages in terms of political mobilizing.

Who gets to mobilize and the possible tensions it can spark

Given the socioeconomic and environmental circumstances here in Pando, the people within some of the categories or types of disability has an easier time mobilizing oneself and fight for their rights and better future. These inequalities concerning opportunities to mobilize reveal the internal conflicts and distrust between the diverse groups, which gives the wish and need for collaboration bad conditions on a practical level.

Physical/ Visual –These are the categories with the highest number of members. The mayor hurdle they face in terms of mobilization is physical accessibility and mobility. Every meeting, social activity, education, or work happens physically in different locations but mostly in the city center, which for the majority means a longer and expensive travel. If they are not able to move around, they are having a hard time participating in these social events or access the given services. It does not take more than a walk around to realize how unfriendly the pavements, different leveling off the streets or public buildings can make life difficult for a person with crutches, in a wheelchair or a person with reduced vision to move around. This is an example confirming Rapp and Ginsburg's (2013) argument regarding that a society not universally designed cannot be fully democratically. Fortunately, family members have become the creative tool to overcome these physical hurdles and create access as discussed in Chapter 3 and some improvements are being implemented in the built physical environment as mentioned in Chapter 4. In addition, I had interlocutors with a visual disability creatively using their enhanced sense of smell (bread indicating bakery, medicine a pharmacy and ink being a printing café) or the use of body memory to navigate around without a service cane. Finally, most people with a physical or visual disability can ride on (or behind someone) on a motorcycle too, which helps with their ability to move around. Though because of the often-long distances they either need one that has the time to bring and collect them or pay big sums for taxis. And since not everyone can afford to pay these sums of money to attend political meetings or social events more than once a week, this confirms Grech's (2015) notion of poverty being a disabling factor in terms of political mobilization.


Couple both with a visual disability. The husband working for the IBC.

The people within the psychical disability category are argued to have one of the highest expenditures for medicine, travel costs and technical helping equipment. Due to the general poverty level, finding the money for these expenses can be a challenge and cause them to be isolated in their homes. The most mobile of my interlocutors in this category are the ones having either an arrangement with a friend – like helping them get around in exchange for a place to live or food – or having a family member driving around. Overall, these architectural barriers in the public spaces, general distances, and the need of help from another person to drive them, can affect the number of people able to active participate or contribute to the mobilization of this group. Previously people within the visual disability category had a materiel disadvantage for mobilizing and participate in the society being the lack of the ability to read text material or use phones, computers, or other technology with a screen, but with the new technology advancement one can activate an ability on the phone or computer, so everything gets red out loud for the person.

The people with visual disability are the group who is the most organized not only here in Pando but in the entire Bolivia. Standing on the shoulders of previous members fighting for their rights, entitled help and better living conditions. As a consequence of being forgotten in the national legislations, the people with a visual disability joined the tradition in Bolivia for the people to mobilize marches or road blockades to illustrate their dissatisfactions. Here they advocated for better conditions and inclusion. This resulted in a national organization for people with a visual disability, IBC, being constructed in 1957 with the purpose of insuring and advocating the rights and improvement needing to be made for the people with disabilities. The most striking difference in terms of benefits the IBC has generated for this category, which differentiate them from the rest, is a higher bonus. An annual bonus of 6200 pesos every April where the people with a severe or very severe disability in the other categories is entitled to 250 pesos every month. In sum this bonus is more than double the size of what the other categories gets. Thereby this category is the only one having an organization advocating for them on a national level. As a result, even though my interlocutors within this category sees the importance of it, this group has a stronger tightness and sense of community and does not have as big of a need as the others for a common collaboration to obtain positive changes.

In comparison when speaking of people with a physical disability in terms of sense of community within the group, I have not experienced or heard of any social activity being made by their association here in Cobija during my fieldwork. This could be explained by many of the people within this category of disability has or has had a job to provide for themselves and has a lesser need for the social aspect of these activities in comparison to people within the auditory, intellectual, or psychic/mental categories, that might feel more isolated or lonely. I found that many people with a physical disability only used their association for knowledge about certain rights, work or help acquiring technical help equipment like a crutch or a wheelchair.

Finally, the biggest advantage these categories have in common in terms of mobilizing is the notion of ‘Nothing about us without us’. This notion emerged in the 1990s from activistic disability movements (Wikipedia 2023). In the context of Cobija/Pando it entails that every powerful position within the area of disability should be filled by a person with disability. At first encounter, this notion made sense to many of my interlocutors and, as I observed especially when interacting with people within the physical or visual disability category. They could grow infuriated if this notion is not followed. Which is interesting because they were the only people able to obtain any of these powerful positions due to the other categories lacking ability to hear/speak out or intellectual/mental abilities. Therefore, at the end of this section, I will illustrate why this notion of every top position filled by the person with the disability might need to be widened a bit to diminish some inequality of mobilization and internalized power relations between the different categories. One of my interlocutors told me that previously the position of director of CODEPEDIS, Miky Maia as well as the president and most of the secretary board of the Federation was filled up by people with a physical disability. But changes are happening because in September the Federation for the first time chose a director of CODEPEDIS to be a lawyer with a visual disability. This illustrates one of the grand advantages found for the people within these categories of disability in terms of mobilizing – they can fight and do advocacy work on their own behalf. Being limited by physical barriers, but without anything wrong with their intellectual abilities or in need of a translator to manage an education or obtaining a job. The point about being able to follow the conversations in the common spaces and using their own physical voice as a tool is exactly what the people in the next category is lacking the ability to, which shows to have a mayor influence on how they can mobilize and participate in advocating work or decision making.

The president for the association for auditory disability, his wife, and another member - all with an auditory disability

Auditory: The association for people with an auditory disability is like the one for psychological and mental disability an association not just for the municipality of Cobija but the whole of Pando because of the few and scattered number of people having this disability throughout the region. Because of their inability to hear or express their opinions or ideas verbally and with the lack of translators or general knowledge of Bolivian sign language, the people within this category have often felt excluded from influence. Left out of decision making, social activities or straight up felt taking advantage of. Additionally, even though seen as a must for the members of this category to learn to strengthen their ability to participate in advocating work or maintaining a regular job, not everyone here with an auditory disability knows how to read. Reading has also been a challenge to learn before the first vocabulary in sign language was constructed in 2016. This adds to the difficulties of mobilizing or possibilities of being taken advantage of by others. Examples I have heard of this feeling of being taken advantage of or forgotten because of their lack of ability to speak up for themselves are 1) being asked to sign contracts without knowing what they entailed 2) being forgotten in the distribution of houses in the barrios. During one of the constructions of houses in Roberto Rojas every category was given eight houses each, except the auditory, which was only provided two.

Interestingly a difficulty for this specific group in terms of mobilizing can also be found amongst its own members and their abilities in terms of sign language. The president of their association explained to me during our interview that Pando as a region has the lowest level of sign language and worst of in terms of access to translators. As an 8-year-old he moved with his family from a coast city in Brazil to Brasiléia, the Brazilian town on the other site of the river, and experienced that his level acquired at his age was higher than the level of some adults here. This could be seen as a consequence of families not educating themselves in sign language or having the possibility to because of grand distances. Pando mainly being filled with small rural communities scattered over a huge size land, you can find a lot of 'natural' sign language speakers as they are called. This means that the parents have taught their kid hand gestures more literally showing what they mean. An example given to me was mom could be making hand gestures for breasts or dad indicating a flat chest with their hands. Understanding the logic behind this seen from their parents' perspective - they need some way to communicate with their child and the child with them - but this provides a difficulty in terms of internal mobilizing or communicating within this group of people. Furthermore, even having access to a translator is not a given in the various municipalities in Pando, like other specialized professional help needed, translators are hard to attract to the countryside because the authorities are only able to pay them a small amount. For example, in Filadelfia a huge municipality in terms of territorial size there was recorded eight people with an auditory disability, two of them was present at the meeting, but not one translator was present or accessible in the municipality.

Often feeling excluded or left out of the social public spaces because of their inability to hear and vocally communicate or others' lacking the ability to communicate in sign language the internal community within this group is strong. They meet up every Saturday to socialize, play sport or make dinner together at the center of Miky Maia. When asked when they felt the most free or happy these gatherings would be the answer. A safe heaven where everyone understood what you were saying, and your self-confidence was boosted. This strong internal community is also emphasized by the fact that most people with an auditory disability marries another person with the same disability.

Most of the people within the group has started an education or acquired jobs, using the technique of meeting up physically at places to ask if they need help ex. with cleaning, office, or factory work. An interesting fact they pointed out to me was that because of their inability to hear, their focus and sight was sharpened and therefore they made efficient workers for detecting productional errors when overviewing factory assembly lines. Others worked in public institutions, which provided an additional difficulty they tried to get erased in their given situation. By law if working in public institutions in Bolivia one must learn one indigenous language. This is arguable because Bolivia now is defined as a plural national state which includes 36 different languages. In general, this is a reasonable requirement to embrace the different people living within one country, but the people with an auditory disability are trying to argue that it should not be a requirement for them as they already must learn reading one new language, Spanish. This law therefore makes it more difficult for the members of this category to mobilize within the labor market.

Even with the difficulties in terms of mobilizing or participating on equal terms with others in the public forums, my interlocuters, Gabriel and Miguel (both having an auditory disability) have a positive outlook regarding the future for the people within their disability category. The lack of translators or knowledge of sign language are making mobilizing difficult, but their strong internal bond, active participating members and only focusing on completing one task at a time makes their association very efficient in completing the goals they set for themselves. During my interviews it is the category people often forget to mention, because they keep to themselves due to the communication barriers. With that said, from observing and interviewing the local translators, the people with an auditory disability have a great help in them, because they do not only view it as their job to translate but also to fight on these peoples' behalf.

Intellectual/Psychic or mental - Merging these two categories together is not to indicate that they are the same or to erase their differences, but in terms of being able to mobilize they face some of the same problems. As Grech found it in the context of Guatemala (2015), both groups need their family members or other people to mobilize and fight on their behalf, which is the same people that also must take care of them and keep the everyday life rolling. Because these family members are often also the providers and helpers, they might not have the same time or surplus in their everyday lives as the people who are able to fight on their own behalf. It also depends on the severity of their child's disability because sometimes a parent might not be able to leave the house and thereby not able to participate in the meetings or social events. A reason for this could be the child acting out or in a state where they are not able to be around other people. There are no institutions or other types of external help, so if the child cannot be brought along, be alone in the house or having another family member able to look after him/her, it is impossible for the parent to participate in anything.

Gathering of members from the association for people with an intellectual disability in Roberto Rojas

On a positive note, developments were happening on this front concerning an until recently forgotten group of children and their parents. Because children being diagnosed with autism are escalating - or at least parents with a child with autism are being more visible in public spaces - an educational option, and more focus on helping them are on the drawing board. People being more visible or open about having a disability in general has according to my interlocutors helped diminishing the stigma from other people or shame of having a child with disability and giving more people the courage to step forward. During my field work, I found the strongest local stigmas were directed towards the people with an intellectual, psychic, or mental disability, because they are less palpable for people to grasp or surrounded by more mystery and lack of general scientific knowledge about them. Therefore, this enhancing courage to step forward with one's disability is an important factor that is needed in order to mobilize the parents or family members of these people. One positive change that can be recorded in this regard is last year only 2-3 families having a child with autism participated in the event on their international awareness day. This year at least 10 families joined the event. They were even planning on having a huge march around the city creating awareness about autism and the people on the spectrum. Unfortunately, this got cancelled because of the flood happening the week before, so it has been postponed to next year instead.

Continuing the subject of the march, this was the main national way of mobilizing and showing one's disapproval of something. During my three months in Cobija I think a march or roadblock was mobilized at least every second week. Unfortunately, my interlocutors found it hard to mobilize or getting people with disability to participate in a march - either because they do not physically or economically have the possibility to, but another issue was found to be people not having the courage to stand forward showing of their disability because of outside stigmas. It is unfortunate because creating public awareness and getting a broader set of actors involved is what Kirakosyan (2016) state is needed to better promote disability rights. But maybe my interlocutors will succeed with a march in the future because there is a slow but positive development of people with a disability being more public.

Beside the difficulties for the people within these two categories regarding political mobilization, beside the people with an auditory disability, I experienced these associations during my fieldwork to be the ones having the most social events for the members to participate in. Addlakha's (2020) findings of care work being oppressive at times for the family members matches my interviews with parents to children with either an intellectual, psychic, or mental disability, where they have all expressed some feeling of being isolated or alone with it all and thereby cut off from the outside world - depending on where they lived and how many family members were there to help them of course. Therefore, I would argue that these families or parents might also be the ones appreciating and needing these social events the most. So, creating opportunities for the parents and the children to socialize with others who either has the same disability or goes through the same things seems important as a counteract to the everyday struggles and experiences of feeling isolated.

I have now illustrated above how the previous mentioned approach of 'Nothing about us without us' in the present moment exclude people with an auditory, intellectual, or psychological/mental disability to be the righteous ones to fill up the powerful positions of the institutions or the federation working and advocating within the area of disability. The argument for this approach is that no one really knows how it is to live with a disability if they don't have one themselves. By having a disability, you have a stronger motivation to fight one step further for the cause. If I am not mistaking the same philosophy is found within organizations working for people with disabilities in Denmark.

In the context of Pando with an already felt unequal situation in terms of being able to mobilize, I found this approach causing a further disadvantage or uneven power relation between the different categories or associations. With people from only two of the five types of disabilities filling up these powerful director positions, the trust of the others in them working for the common good of all and not just their own category needs to be in place for it to work constructively or without anyone feeling less representative. I will not be the judge of what is factual correct in terms of if the people in these positions are actually working for the common good for everyone or not. But considering the amount of gossip, backtalk, or annoyance of the fact only these types of disabilities can fill up these seats now and in the past, I will argue that whether or not it is true, it is still causing a tension or a further division between the people within the different types of disability. Thereby in this case it provides some people with a sense of somebody taken advantage or using their position to only fight for their own group with the same disability (de Beco 2021). Interestingly, the people who are most annoyed with people occupying one of these positions and only being a family member to one with disability are the people with a physical or visual disability.

In my view it is unnecessarily blowing to the fire of an already divided and at times jealous group of people. A disability community, where every group rhetorically wants to collaborate in order for them to appear stronger when knocking down the doors to the authorities, but an idea, suspicion, or belief that other people gets more than them or have the goal to do so, still lives within most of the people here in practice. So, to accommodate or try to dimmish this unequal power dimension of influence felt amongst the different categories I would argue that in the case of the people here in Pando a family member of a person with an intellectual, psychic, or mental disability should be able to fill up these powerful positions. Because of the lack of institutional options, external or specialized help, and the weight placed on family responsibilities and needing to provide everyday care for this person, the parents are affected as much as the person with disability if negative or positive changes was made. This provide the parent with an equal passion to fight for positive changes for people with disability and restore a feeling of being able to obtain some kind of influence. Given their demanding everyday life, they might not even have time or the wish to apply for one of the director or president positions but at least then they got the option. Of course, it should not result in a complete take over, but at least in the beginning I believe it would diminish a feeling of exclusion and distrust.

The president of the association for people with an intellectual disability like the one for psychic or mental disability are occupied by two moms with a child having one of the given disabilities for the same reason. An association is still needed to help these people even though they are not able to run it themselves. They need social opportunities and their close ones a place to go for help and guidance. Because of the lack of translators or people's general ability to understand sign language it would unfortunately for now still be difficult for a person with an auditory disability to occupy one of the powerful positions working within this field. But my general impression regarding the association and community for people with an auditory disability is that it is quite strong and they are satisfied with focusing on their own social community and managing their own problems just them as a group.

Finally, an explanation for the people within the disability community having a hard time mobilizing people or getting them engage in the common fight – beside the distrust of the intention of others - can also be found in the issue of poverty (Grech 2015). Some people might not be able to 'rise to the occasion' as Ginsburg & Rapp (2001) argues in their study of low-income parents to a child with disability in USA. According to most of my interlocutors everyone in the community can find the time and means to engage with mobilizing this political common fight, but: "People just don't want to do anything voluntarily without anything in exchange" was a common phrase heard from my interlocutors in the commission. This was emphasized by the importance of offering lunch to the people attending the meetings in the various municipalities. Their experiences were, that if lunch was not offered, no one would show up. From my experiences attending six meetings in the different municipalities, they are half right. After lunch half of the attendees would leave even though we were only mid-way through the legislation presentation. An explanation for this lack of interest in or ability to engage with the political mobilization by some people within the disability sector in Pando can be due to the socioeconomic life-circumstances or their distrusting beliefs in the possibility to change anything within this corrupt system. Not everyone might have the time to spare or possibility to engage with volunteer work without *intercambio*/exchange. They might feel like the time would be better spent doing anything that can pay them, or they might not be able to leave their house because of their child with a disability not being able to move or engage with other people.

The overview above illustrated how the different constructed disability categories' interaction with the local material conditions provides different advantages or disadvantages in terms of mobilizing political as a group. Furthermore, the overview illustrates, how the complexities found in the social and political life of Cobija/Pando i.e., the local small-town gossip and jealousy culture, tensions between being local or newcomer, and general distrust in other people's intentions if they are not within your network (*Todo es politico*), have been internalized and outplayed within the disability community. By having the concept of 'Nothing about us without us' these categories create their own form of inequality in social life. So, we are left with a paradox between my interlocutors' outspoken necessity and wish for a future common political collaboration across the different categories to generate changes and the messy social affair it is outplayed in practice due to overt structural processes of distrust regarding people outside your own network being internalized and reproduced within the disability community. This paradox will be discussed further below as a conclusion for this chapter.

'Si nosotros no nos organizamos o unimos, nada va a cambiar'

Translated: "If we do not organize or unite, nothing is going to change", this was an expression repeated at every socializing meeting when visiting a municipality, but as I have shown above, this realization has not been easy to activate in practice. These multiple examples of governmentality, lack of transparency, authorities not implementing laws in practice, lack of interest and being politically situated in the opposition - therefore being left to themselves as shown also in Chapter 4 (intersectional) - have all helped construct this paradox of on one side people understanding the need to organize and unite to generate or obtain changes to happen, but on the other side also created this embedded distrust regarding the motives of people from other believes or groups than yourself. Because how can you trust the voluntarily based democracy (wanting the common good) if it does not work on a higher level in your society. Even despite a spark of disbelieve amongst my group of interlocutors regarding if they were even able to change something in practice – based on experiences with general authorities, institutions or voluntarily presidents of the different associations being all talk and no action – the acknowledgment of collaboration amongst people with different disabilities fighting for a common goal, was the only option for generating any kind of change. As illustrated in this chapter, this is easier said than done in practice. I observed a discrepancy between the expressed wish for collaboration with the other associations, to what was outplayed in practice overhearing a lot of slander or jealousy directed towards other associations, claims of people only fighting for their own type or even taking advantages of the fact that their type of disability has an easier time mobilizing.

So even though the people from the commission were preaching this need for uniting and encouraging the people with disabilities and their families to organize and construct their own associations to fight for their common cause in the municipalities we were visiting, they did not always walk the walk themselves yet. But many are trying to work towards it, trying to manage and navigate in this diversity within unity. This general distrust in authorities based on if the politicians even want the population what is best due to the many examples of corruption, if the authorities is telling the truth or basically even interested in helping them, has led to this general distrust of other groups not wanting the common good – only what serves them best. Additionally, an overt diversity beyond the disability categories can be found in Pando in terms of many different cultures gathered within one country (unity), 36 different languages, different ideas of who discriminates or look down on who etc. so these factors can all play a role in this division and distrust of people's attention, ideas of you or secret agendas. In Pando specifically, compared to other regions, a lack of transparency in terms of ex. jobs not being officially listed, intensify the importance of network and connections over qualification, which also enhances this 'look of distrust' and jealousy amongst people within the community: 'He only got that job, house, benefit, help etc. because he knows someone'.

It is all a work in progress and one can see steps being taking towards the collaboration my interlocutors say they need and want. This pilot project is the first time the institutions and associations within the area of disability are collaborating, which might spark more collaboration or unity for future events or projects. At least they are getting to know each other on a more personal level, which is always a start. Furthermore, the pilot project also entails workshops with the goal of promoting better dialogue and understanding of one another's differences both within each individual association but also between them. So, there is hope for more collaboration and less distrust in each other's wishes or motives to take advantage of a powerful position in the future. This acquires a continuous display of willingness amongst my interlocutors to wanting this collaboration to work not only in speech but in practice. For people engaging in the political mobilization to work towards a higher level of planification and holding people accountable for living up to the responsibility of doing what they say they will. Furthermore, the creation of a greater openness about speculations or addressing the prejudice and tensions concerning the ideas of the others, cultural differences, collaboration difficulties or ending the slander about each other is crucial. It is a long and not uncommon process compared to other small-town societies, but it is necessary if they do not want to bring their distrust of general authorities down to the local grass-root level, where collaboration and trust is needed to be able to fight back as a common voice against these same authorities. Generating a successful acknowledgement of the various identities within this idealized unity as Cutajar & Adjoe (2016) suggest is necessary on both a valued and practical level in order to generate a mobilization on a higher level, so one hopefully in the future can engage a broader set of actors in the community and thereby make disability viewed as a public issue to gain further political attention and generating changes within the area (Schneider & Ingram 1993).

Chapter 6: Summary & conclusion

This thesis illustrates that the themes of the local discursive framings of disability, family and care work, the intersection of other material conditions and the access to mobilize are the most vital to explore in order to understand the complex, intertangled and paradoxical relationship between everyday life experiences with 'a difference' and the complexities of social and political life in Cobija/Pando.

The discursive framing of disability takes the responsibility away from the individual and put it on the society but the everyday experience in a region of poverty in poverty (Eide & Ingstad 2011), put the responsibility back on the individual. Even though the legislation states a lot of rights and access to specialized help and care, the everyday life experience with poverty, lack of real political interest or assistance to implement the legislation, and infrastructural breakdown constituting a gothic knot in practice put all the responsibility back on the individual and especially the family. A family that in the practice of everyday life becomes the creative tool for accessing mobilization and participation - the unit of survival for the person with disability. The marginalization of people with disability in the society and politically calls for the different disability categories to unite into a common voice but this is hindered by the general distrust in that others want the best for you in the society.

All this shows the complex, paradoxical and intertangled relationship between everyday life experience and the political and social complexities. Illustrating the importance of understanding the discursive framing of disability, the family's role, the intersectionality, and access to political mobilization on a local and a societal level to get the full picture of how the everyday life is experienced by a person with disability in Cobija/Pando. Through the paradoxes shown across the thesis I have illustrated a discrepancy being present between what is rhetorical valued or expressed vs. what was played out in practices. Demonstrating an interaction and constant negotiation between discourses and material realities, that constantly affects and redesign the everyday life experience of the people with disability living in the region. Within this interplay is the room where 'disability worlds' (Rapp & Ginsburg 2020) is being created, broken down or redesigned in which the people with disabilities are an active part of.

As a final note, regardless of which category they belong to or the different struggles they creatively have to overcome on a daily basis - the general everyday life experience and attitude of my interlocutors can be incapsulated in: "They do what they can with what they have".

Meta-conclusion - "Tú tesis va a ser confundido ¿no? Porque aquí hay de todo"

This phrase: "Your thesis is going to be confusing, right? Because here there is everything" was expressed by an interlocutor, Frederico, in the beginning of our interview after I had just been on his radiobroadcast. Halfway into my fieldwork, this phrase encapsulated everything that I was feeling at once. Confused and overwhelmed by keeping track of all the complexities, contradictions and nuances I kept experiences in terms of the everyday life experiences of my interlocutors and the general social and political life here in Cobija/Pando. And of course, these exists all at the same time when you are dealing with human beings. So, my headache became how can I embrace and faithfully represent all these complexities, contradictions and nuances present at the same time i.e., not ‘suffering objects’ vs suffering materialistic, caring vs. bad manners, family solution vs. problem, home vs. institutionalized, lazy vs. neoliberal approach, government responsibility vs. personal responsibility, oriental (local) vs. occidental (newcomer). How can I be true to my goal and my interlocutors wish to not be viewed as ‘suffering objects’, but at the same time illustrate their struggles in an everyday life context? How can I spark an acknowledging and respected knot from a reader of this paper instead of generating pity? Balancing between not romanticizing and still showing their joys. Illustrating alternative ways of thinking about what is best in terms of care and treatment than the dominant understandings found in Denmark and my own surroundings. I found exploring and writing out the paradoxes allowed me as an ethnographer to “stay with the trouble” (Hartblay 2016) and to represent as faithfully as possible the complexity of this place and peoples’ lives. Pointing towards the fact that, even though slightly confusing, more than one narrative can be present and truthful at the same time.

Even my own conceptions of things changed during my time in the field, revealing unconscious prejudices within myself. A good example of this it regarding the barrios made for people with disability. When I first heard about the concept of a barrio only for people with disabilities I got offended on their behalf and instantly saw it as an isolation organizing tool – removing them from the city center to a place no one encountered them. An even though the first interlocutor I discuss these barrios with sat fire under my own ideas of these houses being given to them for free by the government and political authorities in their municipality was only an election tool to generate votes – this behind laying motive by the authorities was never agreed upon by any other interlocutor. It was something the people less fortunate within the disability community was entitled to by law, though not every political authority in the region remembered to construct them. Realizing most of my interlocuters, even though located a bit far from the city center (Appendix, Map 3), viewed these barrios as a positive thing, my conception changed to embrace the dominant opinion. Shifting my conception to how nice and community-based culture that must dominate here due to everyone living here has something in common. Everyone either having a disability themselves or a family member with one and thereby all encountered or experienced the prejudice and discrimination by the general society. Here no one had to educate others of their worth or abilities to do things. A beautiful utopian image revealing my own prejudices about ‘just because you have a disability, you must get along with everyone else who has one’, forgetting for a moment to consider that other factors like which type of disability, political opinion or originating from outside or within Pando might also have something to say. As I ended up hearing from every person I encountered living in one of the barrios of course there is division, conflicts and discrimination occurring between the neighbors – just like every other small-town neighborhood.

Because I am not able to include or engage myself with every aspect, theme or complexities found during my fieldwork within this single thesis, I have suggestions for future research below.

Future research

Overwhelmed by my amount of data, I have not been able to include or go in depth with everything, therefore I have some ideas for future research. Firstly, a comparative study between other departments in Bolivia or the other side of the bridge in Brazil could have been interesting and giving. Exploring if the categories and experiences of having a disability can travel and change within the same country due to changes in the social, political, or material life. Additionally, comparing Cobija to Brasiilea (Brazil only parted by a short bridge) could be given in seeing how two nations with such a difference in socioeconomic conditions interplay between people with disabilities on either side of the border, who interact on a daily basis but receives totally different types of help from their government. Secondly, research exploring the historical background concerning the social constructed narrative of individual responsibility vs the government. Looking into a country normally divided into smaller societies and therefore not being used to or have good experiences with a central power. I would argue that – as a counterpoint to the global north idea of it just being because of lack of governmental help – it can be seen as more internalized than that looking back on the country's history. Thirdly, work and education aspects – ideas for creating more jobs or educational options (the new being autism). Fourthly, I would love to go back after the pilot project is finished in January to see if any changes have happened especial in terms of collaboration across the different disability categories.

Bibliography

- Addlakha, R. (2020) "Kinship destabilized!," *Current Anthropology*, 61(S21), pp. S46–S54. Available at: https://doi.org/10.1086/705390.

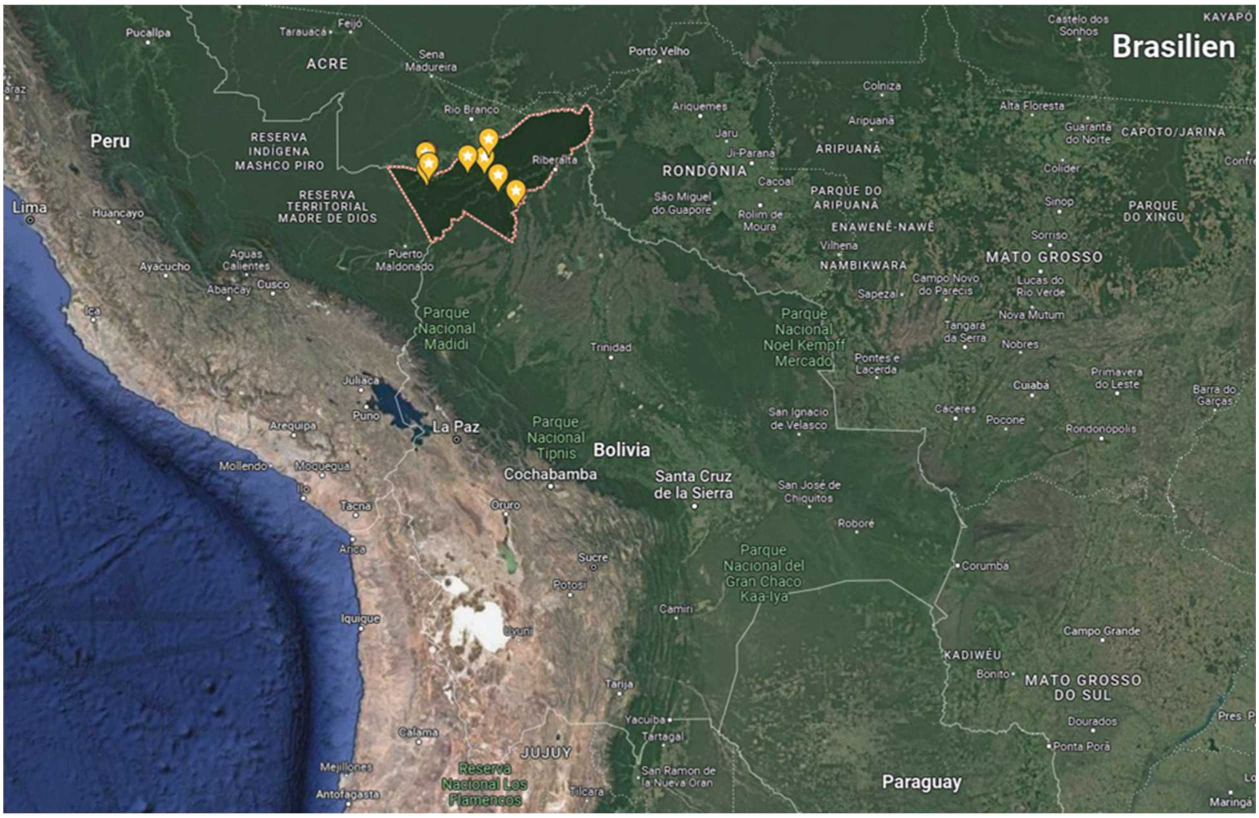
- Braff, L. (2020) *Chapter 15: The Global North: Introducing the Region*. Available at: https://milnepublishing.geneseo.edu/genderedlives/chapter/chapter-15-the-global-north-introducing-the-region/.
- Crenshaw, K.W. (1991) “Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color,” Stanford Law Review, 43(6), p. 1241. Available at: https://doi.org/10.2307/1229039.
- Cutajar, J. and Adjoe, C. (2016) “Whose knowledge, whose voice? Power, Agency and resistance in disability studies for the Global South,” in *Springer eBooks*, pp. 503–516. Available at: https://doi.org/10.1007/978-3-319-42488-0_32.
- Defensoria del Pueblo. (2012) *Derechos Humanos de las personas con discapacidad.* Retrieved from https://www.defensoria.gob.bo/uploads/files/derechos-de-las-personas-con-discapacidad-cartilla.pdf
- De Beco, G. (2021) *Disability in international human rights law*, *Oxford University Press eBooks*. Available at: https://doi.org/10.1093/oso/9780198824503.001.0001.
- Dokumaci, A. (2023) *Activist affordances: How Disabled People Improvise More Habitable Worlds*. Duke University Press.
- Eide, A.H. and Ingstad, B. (2011) *Disability and poverty*, *Policy Press eBooks*. Available at: https://doi.org/10.1332/policypress/9781847428851.001.0001.
- Ginsburg, F., & Rapp, R. (2001). Enabling Disability: Rewriting Kinship, Reimagining Citizenship. *Public Culture* 1 September 2001; 13 (3): 533–556. doi: https://doi.org/10.1215/08992363-13-3-533
- Ginsburg, F., & Rapp, R. (2020). Disability/Anthropology: Rethinking the Parameters of the Human. *Current Anthropology*, *61*(S21), S4–S15. https://doi.org/10.1086/705503
- Ginsburg, Faye, and Rayna Rapp. 2013. “Disability Worlds.” Annual Review of Anthropology 42: 53–68'
- Grech, S. (2015) *Disability and poverty in the global South*, *Palgrave Macmillan UK eBooks*. Available at: https://doi.org/10.1057/9781137307989.
- Grech, S. and Soldatic, K. (2016) *Disability in the global South*, *Springer eBooks*. Available at: https://doi.org/10.1007/978-3-319-42488-0
- Hartblay, C. (2020) ‘Disability Expertise: Claiming Disability Anthropology’, *Current Anthropology*, 61(S21)
- Haraway, D. (2016). *Staying with the Trouble*. https://doi.org/10.1215/9780822373780

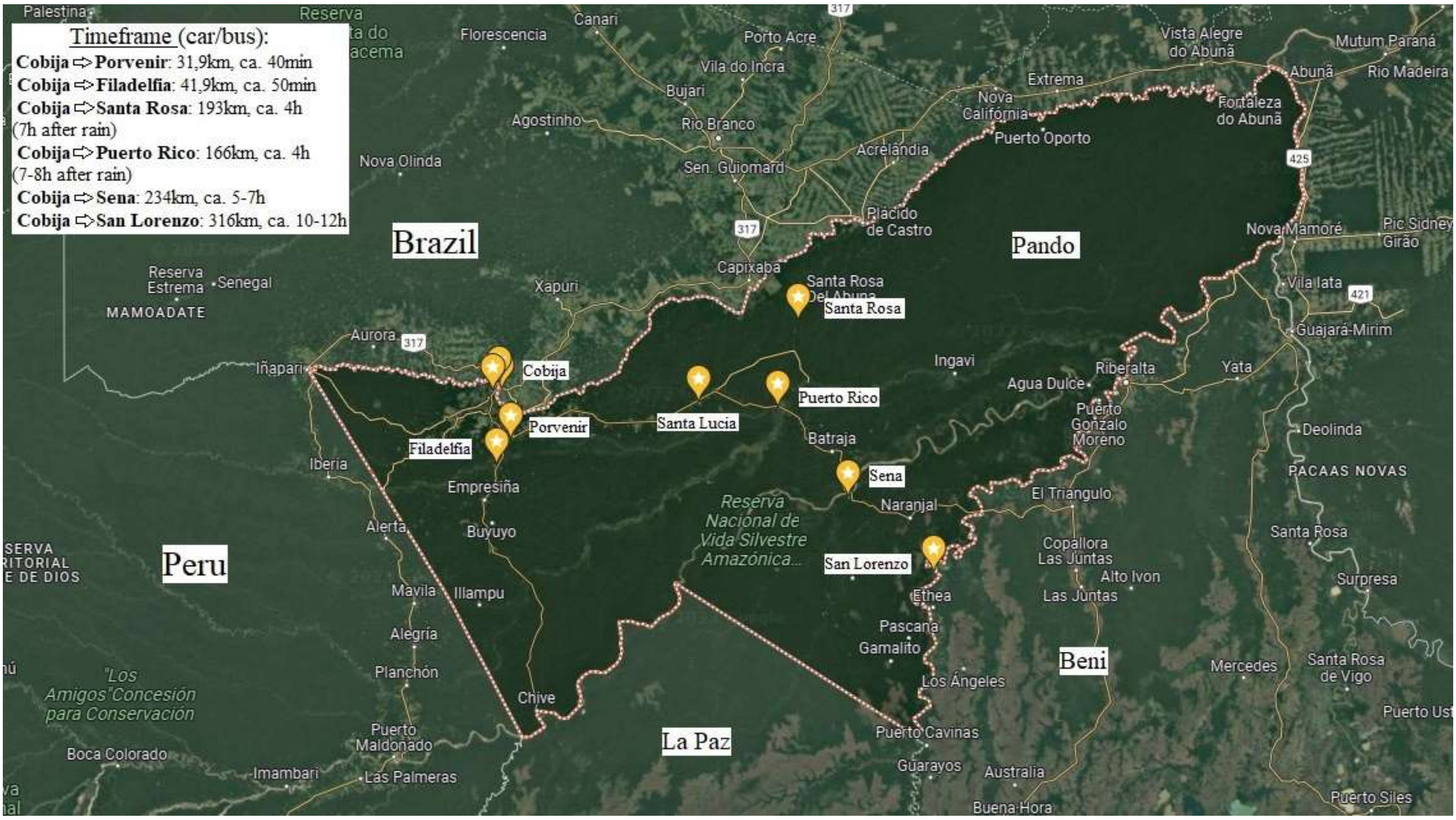
- Kirakosyan, L. (2016) ‘Promoting Disability Rights for Stronger Democracy in Brazil: The Role of NGOs’, Nonprofit and Voluntary Sector Quarterly, 45(Special Issue), p. 114S–130S.
- Kulick, D. and Rydström, J. (2015) *Loneliness and its opposite: Sex, Disability, and the Ethics of Engagement*. Duke University Press Books.
- Ma, Z. (2019, January 15). *Family*. Somatosphere. http://somatosphere.net/2019/family.html/
- McCarthy, H. (2021) ‘Self-Advocacy and Ally-Advocacy for Disability Justice: Organisational, Psychosocial, and Political Resources’, *Disability, CBR & Inclusive Development*, 32(2), pp. 160–178. doi:10.47985/dcidj.402.
- Mills, C. and Davar, B.V. (2016) “A local critique of global mental health,” in *Springer eBooks*, pp. 437–451. Available at: https://doi.org/10.1007/978-3-319-42488-0_28.
- OHCHR (2006) Convention on the Rights of Persons with Disabilities. Available at: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities.
- Reno, J. *et al.* (2021) ‘Toward a Critical and Comparative Anthropology of Disability: Absent Presence and Exemplary Personhood’, *Social Analysis*, 65(3), pp. 131–149. doi:10.3167/sa.2021.650307.
- Schneider, A. and Ingram, H. (1993) ‘Social Construction of Target Populations: Implications for Politics and Policy’, The American Political Science Review, 87(2), pp. 334–347.
- Stark, L. (2020) “Ethnographic challenges to studying the poor in and from the Global South,” in *Challenges and solutions in ethnographic research*. Routledge.
- UN. (2006). Article 1 – Purpose | United Nations Enable. un.org. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html
- Wickenden, M. and Elphick, J. (2016) “Don’t Forget Us, We Are Here Too! Listening to Disabled Children and Their Families Living in Poverty,” in *Springer eBooks*, pp. 167–185. Available at: https://doi.org/10.1007/978-3-319-42488-0_11.
- Wikipedia contributors. (2022). Inequality in Bolivia. Wikipedia. https://en.wikipedia.org/wiki/Inequality_in_Bolivia

- Wikipedia contributors. (2023). Nothing about us without us. *Wikipedia*. https://en.wikipedia.org/wiki/Nothing_about_us_without_us
- Wikipedia contributors. (2023b). Movimiento al Socialismo. Wikipedia. https://en.wikipedia.org/wiki/Movimiento_al_Socialismo
- Wikipedia contributors. (2023c). Pando Department. *Wikipedia*. https://en.wikipedia.org/wiki/Pando_Department
- Wool, Z.H. (2015) *After war: The Weight of Life at Walter Reed*. Duke University Press

Appendix

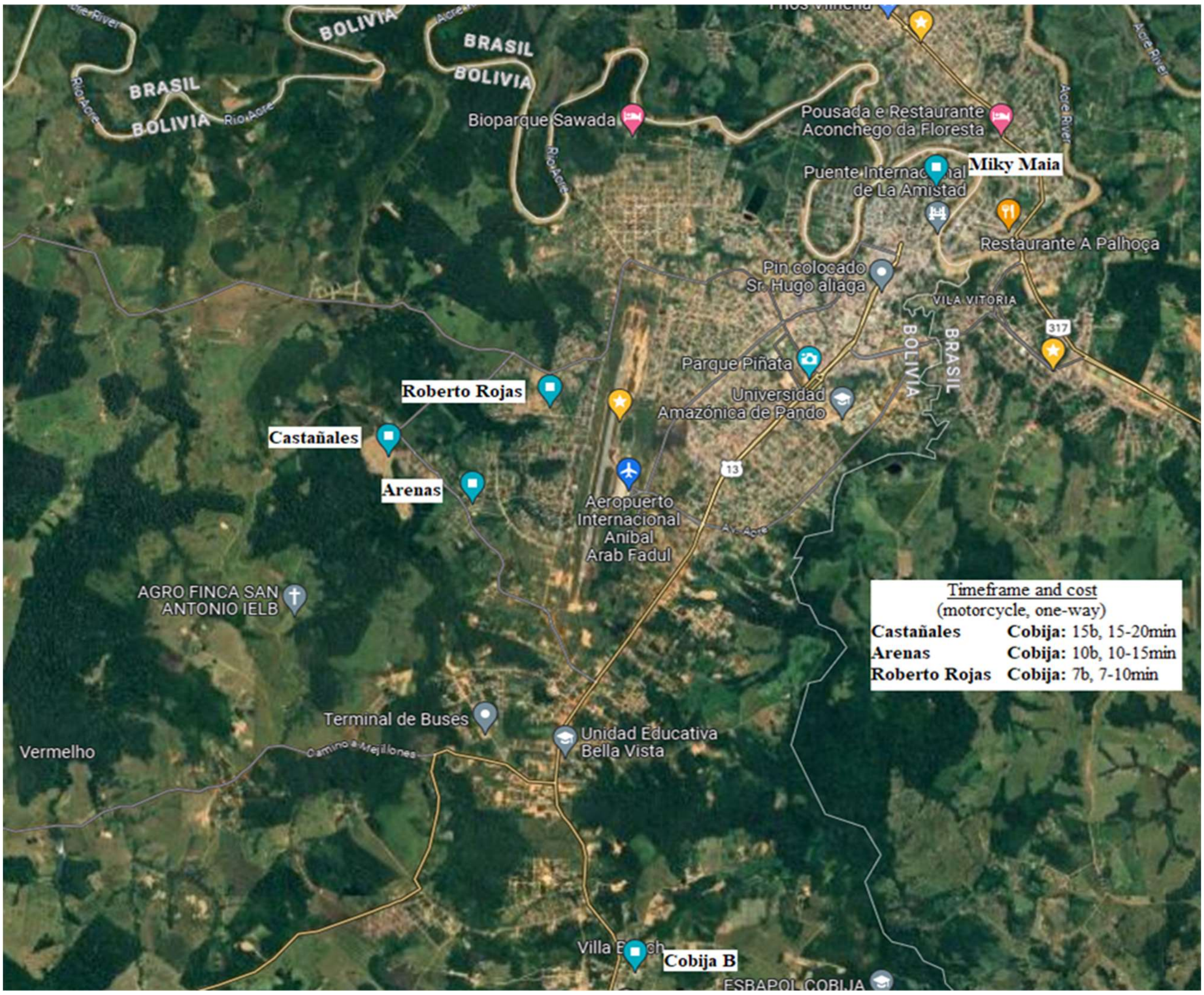
1. *Maps with inscribed distances (Bolivia, Pando, Cobija)*





Timeframe (car/bus):

Cobija ⇨ Porvenir: 31,9km, ca. 40min
Cobija ⇨ Filadelfia: 41,9km, ca. 50min
Cobija ⇨ Santa Rosa: 193km, ca. 4h (7h after rain)
Cobija ⇨ Puerto Rico: 166km, ca. 4h (7-8h after rain)
Cobija ⇨ Sena: 234km, ca. 5-7h
Cobija ⇨ San Lorenzo: 316km, ca. 10-12h



Timeframe and cost
(motorcycle, one-way)

Castañales	**Cobija:** 15b, 15-20min
Arenas	**Cobija:** 10b, 10-15min
Roberto Rojas	**Cobija:** 7b, 7-10min

2. *Fieldwork schedule*

PLAN DE VISITA CECILIE, FECHA: Del 8 marzo al 1 de junio 2023

FECHA	HORA	LUGAR	ACTIVIDAD	OBSERVACIONES
08.03.23	11.00		Llegada a Cobija	
09.03.23	15.00–17.00	Miky Maia	Reunión con la Federación Departamental: Tema Planificación	
10.03.23	9.00	Sena	Visita a una provincia – socialization of law and organization	The president of the Federation and her daugther (ayuda)
11.03.23	9.00	Sena	Visita a una provincia – socialization of law and organization	The president of the Federation and her daughter (ayuda)
12.03.23			Lunch with an interlocutor	
13.03.23			PLANIFICACIÓN by Eduardo	
14.03.23			Lunch with an interlocutor	
15.03.23	15.00	Miki Maia	Reunión con la Comisión de Dirección del proyecto de evaluación y planificación	
16.03.23	9.00	Miki Maia	Entrevista con el director con UMADIS	
	14.00	Alcaldía	Visita a la Alcaldía	Reorganizar – she never had the time
	17.00	Puerto Rico	Visita al Municipio de Puerto Rico – socialization of law and organization	Henry, Maria, Janet, la hija de Henry (ayuda)
17.03.23		Puerto Rico	Visita al Municipio de Puerto Rico – socialization of law and organization	Henry, Maria, Janet, la hija de Henry (ayuda)
18.03.23	9.00	Roberto Rojas	Festejo por el día del padre. ASOPADIC	
19.03.23			LIBRE	
20.03.23	15.00	Miki Maia	Entrevista con la Asociación de discapacidad intelectual ASOPADIC	With the president of the association
21.03.23	9.00	Centro de educación especial, Cobija B	Dia de Sindrome de Down	Celebration with the whole school and all their students
	14.00	Comando de la Policía	Dia de Sindrome de Down. Miss y Mister Down	Beauty pageant for the children with Down Syndrome
22.03.23	9.00	Miki Maia	Aniversario Miki Maia	Celebration event with the disability community using Miki Maia
23.03.23	15.00 19.00	Miki Maia Radio del Acre	Reunión con la Comisión de Dirección del proyecto de evaluación y planificación Interview in interlocutor's radio show	
24.03.23			Lunch with an interlocutor and her lawyer friend	

25.03.23		Porvenir	Visitar al Municipio de Porvenir – socialization of law and organization *Flood and the evacuation start*	Maria, Henry, Jhamil, Luciel, Carlos, Emelina (tolk)
26.03.23		Community house for their association The low part of the city – include Miki Maia	Actividad y Entrevista con la Asociación ACRE (Personas ciegas) *Helped with the evacuation of people living in the soon to be flooded areas*	Gathered 12 people with a visual disability – group interview
27.03.23			LIBRE	
28.03.23	10.00	Miki Maia	Entrevista con la Asociación de discapacidad Física	
29.03.23	18.00		Barrios Roberto Rojas, barrio las arenas, y Castañal	Visita a diferente gente con Discapacidad
30.03.23			Barrios Roberto Rojas, barrio las arenas, y Castañal	Entrevistas gente con discapacidad
31.03.23	20:00	San Lorenzo	Barrios Roberto Rojas, barrio las arenas, y Castañal *Helped clean up Miki Maia after the flood.* Bus ride	Viven las personas con Discapacidad
01.04.23	9.00	San Lorenzo	Visita al Municipio de San Lorenzo – socialization of law and organization	Luciel, Maria, Zaida
02.04.23	9.00 18.00	San Lorenzo Parque Piñata (Cobija)	Visita al Municipio de San Lorenzo Día del Autismo. Actividad de la asociación de discapacidad psíquica	
03.04.23	16.00	Casa de Janet	Día del Autismo. Actividad de la asociación de discapacidad psíquica	
04.04.23			LIBRE	
05.04.23	8.30 10.00		*Reunión con Eduardo y Nancy* Entrevista con Henry, director de CODEPEDIS	
06.04.23	8.30	COBIJA B	Entrevista y fútbol a COBIJA B	
07.04.23			Dinner with an interlocutor	
08.04.23	9.00		Entrevistas a personas con Discapacidad barrios Roberto Rojas y Arenas	
09.04.23			LIBRE	
10.04.23	9.00 14.30 18.00	Miki Maia Miki Maia Radio del Acre	Entrevista con Emelina Miki Maia, directora Reunión de la Comisión de Ejecución de Proyecto	

			Entrevista con Jhon Gonzales, presidente de la asociación de los deportes y radio	
11.04.23			LIBRE	
12.04.23	9.00	Miki Maia	Entrevista con la Asociación de discapacidad Psíquica	
13.04.23			Lunch with an interlocutor	
14.04.23	8.00		Entrevista y visita a COBIJA B	
15.04.23	10.00 16.00	Miki Maia Miki Maia	El día de los niños con discapacidades Entrevista con la Asociación de Personas Sordas ASORPANDO	
16.04.23			LIBRE	
17.04.23	El día	Filadelfia	Visita al Municipio de Filadelfia – socialization of law and organization	Irene, Israel, Janet, the guy from defensoria
18.04.23			Joining a religious célula with an interlocutor	
19.04.23	11.00	Different barrios	Visita a casas a personas con discapacidad con Robert, fisioterapeuta	
20.04.23			LIBRE	
21.04.23	10.00 12.30		Visita y breve entrevista a la oficina de SEDEGES Lunch and interview with an interlocutor	
22.04.23			LIBRE	
23.04.23			LIBRE	
24.04.23	9.00	Miki Maia	Reunión con Israel – proyecto foto y preguntas practicas	
25.04.23	14.30	Miki Maia	Reunión con la comisión	
26.04.23			LIBRE	
27.04.23			LIBRE	
28.04.23			LIBRE	
29.04.23		Roberto Rojas (barrio)	Teach two interlocutors English and informal talk	
30.04.23			LIBRE	
01.05.23		House of an interlocutor	Día de los trabajadores	Home dinner with a group of interlocutors
02.05.23			LIBRE	
03.05.23	14.30	Miki Maia	Reunión de la Comisión de Ejecución de Proyecto y Eduardo	
04.05.23			LIBRE	
05.05.23		Santa Rosa	Visita al Municipio de Santa Rosa – socialization of law and organization	
06.05.23		Santa Rosa	Visita al Municipio de Santa Rosa	
07.05.23			SICK/trying to write	
08.05.23			SICK/trying to write	
09.05.23			SICK/trying to write	
10.05.23			SICK/trying to write	
11.05.23			SICK/trying to write	
12.05.23			SICK/trying to write	

13.05.23			SICK/trying to write	
14.05.23			SICK/trying to write	
15.05.23			LIBRE	
16.05.23	18.00		Entrevista con El Defensoría del Pueblo	
17.05.23		Miki Maia	Hanging around Miki Maia	Informal talks
	17.00	Roberto Rojas (barrio)	*Foto and empowerment project* – two mothers to girls with Down Syndrome	Interview and stuff to do a sensibilization project
18.05.23	17.00	Outside Cobija	*Foto and empowerment project* – mother and family to a girl with schizophrenia	Interview and stuff to do a sensibilization project
19.05.23	16.00	Castañales (barrio)	*Foto and empowerment project* – Visiting and talking to the families with visual disability in the area	
20.05.23		Castañales (barrio)	Spending a whole day in the area	
21.05.23		Sister´s house to an interlocutor	Spending a whole day with the family of an interlocutor	
22.05.23	12.00	Arenas (barrio)	Family birthday for an interlocutor	
23.05.23			LIBRE/write	
24.05.23			LIBRE/write	
25.05.23			LIBRE/write	
26.05.23			LIBRE/write	
27.05.23	12.00	House o fan interlocutor	Common family lunch with a group of interlocutors	Día de la madre – important here
	18.00	Sister´s house to an interlocutor	Family celebration of Mother's Day with an interlocutor	
28.05.23			LIBRE	
29.05.23		Stadium	Football match with interlocutors	
30.05.23		Miki Maia	Workshop with the comisión and association members – focus on promoting dialogue	Gathered around 20
31.05.23		Miki Maia	Workshop with the comisión and association members – focus on promoting dialogue.	Gathered around 20
	12.00	Miki Maia	My presentation and thank you to my interlocutors.	
	18.00	House of an interlocutor	Goodbye dinner and karaoke arranged by the commission	
01.06.23			Salida de Cobija	

3. *Overview of interview interlocutors*

List of people you meet - interlocutors	
Josef (UMADIS)	Luisa (Roberto Rojas, Commission)
Janet (Association for the people with intellectual disability)	Maria (Roberto Rojas, Commission)
The association for the blind (Juan and 8 other members)	Biviana (Miky Maia, sign translator)
Martín (Association for people with physical disability)	Frederico Gonzalez (Sport association, radio host)
Laila (Roberto Rojas x2)	Sofia (Association with mental and psychic disability)
Jorge (Roberto Rojas x2)	Cecilia (son with depression, many informal talks)
Family with a boy with Down Syndrome (Roberto Rojas)	Women in wheelchair with Jean (see phone notes)
York (CODEPEDIS)	Brief talk with family in Castañales with Jean (far away)
Maurice (Cobija B x2)	Gabrial and Miguel (Association for the people with auditive disability)
Emilio Mendez and mom (Arenas)	Brief with Laila and Jean fra SEDEGES
2 mothers both with an autistic child	Luis (the guy from Por venir)
Maria del Carmen (informal talks)	