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# The life conditions of people with intellectual disabilities in Nepal



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## Foreword

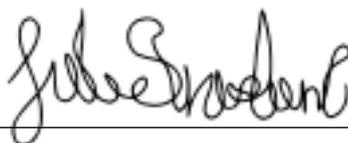
In this project we have used literature from the subject Human Rights. We have especially used literature from the thematics *Universalism and relativism*, *Institutionalization of human rights: International institutions and the impact of human rights* & *Human rights and business*. The literature is mainly used in the literature review in the following sections: “*UN and The Universal Declaration of Human Rights*” and “*Non-Governmental Organizations*”. To gain a better understanding of the UDHR and what it contains, we have used the text “*Human Rights*” by Baylis, Smith and Owens from the book “*The Globalization of World Politics*”. Furthermore, the text is used to get knowledge about the increase in the number of NGOs. To understand the complexity of implementing the universal human rights we have used Nickel’s text “*Is Today’s International Human Rights System a Global Governance Regime*”. Moreover, this text gives us insight in the work of NGOs and their role in advocating human rights. To define human rights and to achieve a critical perspective on the universalism of the human rights we have used “*The concept of human rights*” by Renteln. Another text that argues the universalism of the human rights is Niezens’ text “*Relativism and Rights*” from the book “*The Origins and Indigenism: Human Rights and the Politics of Identity*”. Furthermore, this text also explains how the human rights were developed. Finally, we have used the text of Pillay – “*The Corporate Responsibility to Respect: A Human Rights Milestone*” to get a wider understanding of an article in the UDHR. This literature will in the discussion section be compared to our empirical results and hereby we will discuss the universalism of the human rights in relation to people with intellectual disabilities in Nepal.

## Tro og love erklæring

*"Det erklæres herved på tro og love, at undertegnede egenhændigt og selvstændigt har udformet denne rapport. Alle citater i teksten er markeret som sådanne, og rapporten eller væsentlige dele af den har ikke tidligere været fremlagt i en anden bedømmelsessammenhæng."*



Caroline P. L. Henriksen



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## **1. Introduction**

### **1.1 The establishment of United Nations and the Convention on the Rights of People with Disabilities**

In 1945, the intergovernmental organisation United Nations (UN) was founded with the purpose of making peace and prevent war. Today, the UN primarily focuses on upholding international law, protecting human rights and promoting democracy (United Nations), which for example is expressed by the Convention on the Rights of People with Disabilities (CRPD), that was maintained in 2006. CRPD secures people with disabilities rights to equality, dignity, autonomy, participation and inclusion in society. It is important to ensure their rights, because people with intellectual disabilities often experience stigmatization, discrimination, neglect and abuse (Kanter, 2014). The Convention has described disability in a social and rights-based perspective, which is a change in the way the society views people with disabilities, where previously, society viewed them as objects of social protection and medical treatment. This means that there now is a more social view on people with disabilities instead of a medical view (National Federation of the Disabled - Nepal (NFD-N), 2016). As one out of many countries, Nepal also agreed on the CRPD in 2010 (Ibid.).

### **1.2 Culture and religion in Nepal**

In Nepal there has been a development which has increased focus on people with disabilities' rights. Despite of this development, Nepal is still dealing with cultural issues that has an impact on people with disabilities. These cultural issues are mostly caused by the caste system, which is connected to Hinduism. 87 percent of the population in Nepal are Hindus, and until 2006 Hinduism was the state religion. This means that Hinduism and the caste system is deeply rooted in the Nepalese culture (Møller-Kristensen, 2017). The system creates a very hierarchical framework in the society (Nielsen, 2001: 15).

### **1.3 Disabilities in Nepal**

Because of their religious life, most people in Nepal consider disability a consequence of a sin committed in a former life. This thought amongst the population has caused discrimination, abuse and violence against disabled people. This is also reflected in the media where reports are published with negative stereotypes on disability which affects the mentality of people in Nepal towards people with disabilities (NFD-N, 2016). This attitude and stigmatization towards people with disabilities are the reason why a number of organisations have been founded to improve the conditions for disabled, e.g. National Federation of the Disabled - Nepal (NFD-N) and Parent Federation of Persons with Intellectual Disabilities (PFPID).

NFD-N is an umbrella organization and represents more than 350 disabled people organizations. It is a leading national body of the disability rights movement in Nepal, where it is promoting the rights of people with disabilities (National Federation of the Disabled - Nepal, 2016). PFPID was founded in 2011 and is also an umbrella organisation with 43 networks among the districts in Nepal. PFPID is a non-governmental organisation which works to ensure rights of persons with intellectual disabilities (PWID) and their families. Their vision is “an inclusive society for people with intellectual disabilities, where they realize their human rights, equality and respect” (PFPID).

#### **1.4 Our problem field**

We find it interesting to examine this field, because PWID are an exposed minority in Nepal. Moreover, there is not a lot of research within this field. Therefore, we would like to illuminate the daily life challenges of PWID and emphasize how the Nepalese culture and traditions affect their life conditions. In relation to examining this, we have chosen to collaborate with PFPID, as they are one of the only NGOs fighting for PWID' rights. Furthermore, we would like to examine if it is possible for PWID to feel included in society, and what PFPID does to achieve this. Therefore, we find it relevant to examine the following thesis statement:

*What kind of challenges do people with intellectual disabilities experience in Nepal, and how does the NGO Parent Federation of Persons with Intellectual Disabilities seek to improve the life conditions of these people?*

To examine this, we have chosen a critical phenomenological approach where we will conduct 10 semi-structured interviews and participating observations. To analyse our empirical results, we will use the capital forms of Bourdieu and Honneth's theory about recognition theory as our theoretical framework.

## 2. Literature review

In this literature review we will describe the establishment of the Universal Human Rights, and present different views on these. Moreover, we will explain the growth in the number of Non-Governmental Organizations and how they operate with the Human Rights. In relation to this we will describe the NGO PFPID and how they work with intellectually disabled people in Nepal. Afterwards we will review people with intellectual disabilities' life conditions and what prevents them from getting equal rights.

### 2.1 UN and The Universal Declaration of Human Rights

After the second world there was a growing awareness on the horrors of the holocaust, which lead to the establishment of the United Nations and the Universal Declaration of Human Rights (UDHR) in 1948. UDHR is a list of internationally accepted human rights, which means that they are interdependent and universal. The national states that are a part of the declaration are committed to implement the international human rights in the best possible way. However, it can be difficult because the states do not have the needed procedures to implement these (Baylis, Smith & Owens, 2011:496). Therefore, the UDHR is more inspirational than legally binding (Nickel, 2002: 357). To ensure a common perception of the universal human rights a definition has been created:

"A human right is a universal moral right, something which all men, everywhere, at all times ought to have, something of which no one may be deprived without a grave affront to justice, something which is owing to every human being simply because he is human" (Renteln, 1988: 347).

The human rights were developed by "technical experts" with the purpose of achieving morality that goes beyond culture and religion (Niezen, 2003: 96). The declaration contains 30 articles which includes both political, civil, social, economic and cultural rights (Pillay, 2008: 2). Even though the UDHR seeks to universalize the human rights, it is criticized of being constructed by the western states and therefore based on western values (Baylis et al., 2011: 507). This is caused by the fact that the Third World was not included when the declaration was created (Renteln, 1988: 351). The UDHR is also criticized especially in Asia for not being equal as the "right to development and economic progress should take precedence over free speech and democratic development, that a people cannot be free until they are fed, and that firm political control is the first requirement of prosperity" (Niezen, 2003: 96).

It is difficult to argue that the human rights are universal because “underlying the presumption of universality is the belief that all people think in a similar fashion” (Renteln, 1988: 349). This is critical because the universal ethics and norms are forced upon different cultures, which have diverse values (Niezen, 2003: 94-95).

The implementation of the human rights can only succeed with knowledge of different cultures and the development can only arise by the recognition of these (Niezen, 2003: 109).

## **2.2 Non-Governmental Organizations**

Since the Universal Declaration of Human rights was proclaimed, there has been a growth in international human rights organizations, who have become important figures in spreading awareness of international Human Rights (Nickel, 2002: 354, Baylis et al., 2011: 503-504). NGOs mainly inform people about their rights and expose human rights violations by advocating. They are political organisations representing perspectives of some people rather than people in general (Nickel, 2002: 369).

## **2.3 Parent Federation of Persons with Intellectual Disabilities (PFPID)**

In 2008 there were more than 200 NGOs working for improving the life conditions of people with disabilities in Nepal (Crishna & Prajapati, 2008: 135). One of them is PFPID, whose overall goal is: “empowering and ensuring People with Intellectual Disabilities and their Parents to become conscious about their rights to entitlements, participation, security, freedom, human dignity and quality of life”. PFPID operationalizes this goal by, among other things, advocacy, which is a way to ensure people with intellectual disabilities’ social and political rights. The advocating consists of publishing media stories, making press releases and organizing awareness campaigns. By advocating PFPID provides suggestions and feedback to the government. In order to support the advocating PFPID also does research on their life conditions, where the data and statistics are used to design projects and trainings for people with intellectual disabilities and their parents. The data and statistics are being exchanged between collaborating organizations to gain knowledge resources about people with intellectual disabilities in different countries. By gaining this knowledge PFPID pays attention to the different needs amongst people with intellectual disabilities. Because people with intellectual disabilities have different needs than the rest of the population, they should be entitled to special services which the government is obligated to provide (PFPID).

## **2.4 Intellectual disabilities**

People with intellectual disabilities often feel discriminated and are met with different prejudices which makes them fear speaking about their disabilities, because they are afraid of being stigmatized (Kanter, 2014). The government of Nepal has defined an intellectual disabled as: “an individual having difficulty in carrying out activities relative to age or environment due to absence of intellectual development before age of 18 years” (Government of Nepal, 2014: 356). People with intellectual disabilities can be classified into two categories: the first classifies people that are able to manage daily activities like eating and getting dressed with training, and the other classifies people that cannot manage daily with training (Crishna & Prajapati, 2008: 134). The Population Census from 2011 shows that almost 2 percent of the population in Nepal have a disability where 3 percent of the 2 percent are intellectual disabled (Eide, Neupane & Hem, 2016: 59). This number may not be accurate due to lack of data, which may be caused by people not informing about their disability (Crishna & Prajapati, 2008: 133).

One of the obstacles of improving the life conditions of people with intellectual disabilities is the attitude towards them from society (Brandt, 2015: 39). Due to lack of resources, families with intellectual disabled relatives are not able to take care of them. Sometimes the parents are forced to chain their relative with intellectual disabilities when they leave for work, as they need to provide their family with an income (NFD-N, 2016). It is also seen that parents leave their new-born intellectual disabled child, as they cannot provide them with the needed resources (Kanter, 2014). Except from the lack of resources people in general do not have the necessary information about people with intellectual disabilities. Another aspect that prevent society from accepting people with intellectual disabilities is religion. Due to religion most families want their intellectual disabled child to become “normal”, which prevent them from developing their knowledge about the intellectual disability and how to promote the development of their child. In that context it is important for the population to learn how to value people with intellectual disabilities instead of stigmatizing and marginalizing them (Crishna & Prajapati, 2008: 133).

## **2.5 A clash between legislation and reality**

To improve the life conditions of people with intellectual disabilities the government in Nepal in the 1980's and in the 1990's adopted several legislations, such as social welfare act, children protection act and education act (Brandt, 2015: 23). These acts include establishment of day-care centers, free education, services and facilities (Crishna & Prajapati, 2008: 133). Many of these facilities are located in the bigger cities, which means that people with intellectual disabilities living in rural areas do not have access to these (NFD-N, 2016).

Research from the Population Census shows that only 41,3 percent of children with disabilities are benefiting from educational services (Eide, Neupane & Hem, 2016: 36-37). This means that many disabled children do not develop essential life skills (Crishna & Prajapati, 2008: 133). Despite of the fact that some children with disabilities are under education they experience discrimination and humiliation, which is critical as especially children with intellectual disabilities are more vulnerable when it comes to discrimination and social exclusion (Brandt, 2015: 17). Another issue regarding the educational institutions is that they do not provide the needed facilities to accommodate their disabilities (Eide, Neupane & Hem, 2016: 38).

Even though there has been adopted a number of legislations focusing on improving the facilities of persons with intellectual disabilities, they have not been implemented optimally. Despite of the improvement in people with intellectual disabilities' life conditions: "there is a very wide gap between needs and demands and the actual provision and availability of services" (Crishna & Prajapati, 2008: 134). Previous studies indicate that the main issue is not the lack of implemented legislations but more specific society's attitude towards people with intellectual disabilities. Therefore, the suggested solution is that society should raise awareness about people with intellectual disabilities and learn how to understand them (Crishna & Prajapati, 2008: 133).

The above mentioned literature show that universal human rights have been drafted, however the implementation of these are lacking because of cultural differences and diverse values. This is exemplified in Nepal where people with intellectual disabilities still experience discrimination and stigmatization despite of the adopted CRPD. Therefore, we would like to examine the life conditions of people with intellectual disabilities and what PFPID does to improve these. Subsequently we will compare our empirical data with the above literature.

### **3. Method**

In the following section we will describe our scientific theoretical approach and how this has affected both our data collection and processing, including semi-structured interviews, participating observations and coding. Finally, we will discuss the validity of our examination.

#### **3.1 Scientific theoretical approach**

We have chosen the phenomenological scientific approach as our thesis is based on the individual experiences and understandings of our interview persons. The focus of the phenomenology is to understand social phenomena from the individual's perspectives. This means that the reality is what individuals perceive it to be (Kvale & Brinkmann 2015: 48). Therefore, the purpose is to examine how individuals experience situations and how the situations affects their reality (Nordentoft & Olesen 2014: 18). In our research the focus has been the staff of PFPID and the parents of children with intellectual disabilities, as they experience the daily life challenges of people with intellectual disabilities. To examine this, we have omitted our prejudices and especially our cultural pre-understanding when conducting the data to have an objective approach towards our interview person's reality (Juul, 2012: 70). However, we have been critical in relation to our phenomenological approach in the analysis of our data, which means that we have used hermeneutical strategies when interpreting our empirical results. This is especially expressed, when we are critically interpreting the parents' causal explanations of their child's condition and the work of PFPID. We have chosen to be critical, as we have found it relevant to include our own cultural perspectives in relation to understanding and interpreting the culture in Nepal.

#### **3.2 Data collection**

This project is based on qualitative methods including semi-structured interviews. Furthermore, we have used an empirically inductive research approach, which means that our data is not limited by a predetermined theoretical frame before we collected the data. Because of the fact that we did not have a theoretical angle we were compelled to be open minded towards the field. This means that we continuously evolved a better understanding of the subject. Therefore, our theoretical frame is based on the empirical data collection (Kristiansen, 2010: 451-452).

#### **3.3 Collection of literature**

In the process of collecting literature we found it difficult in general to find relevant studies, the reason being a lack of information about intellectual disabilities in Nepal. Most of the available literature are in Nepali, and

besides that there is a lack of quantitative data. Therefore, we have used the method chain search, which means that when we found useful literature, we followed the references and found more relevant studies (Rienecker & Jørgensen, 2012: 148).

### 3.4 Semi-structured interviews

We have chosen the semi-structured interview, because this method is great for uncovering tacit knowledge as well as individual interpretations of a phenomenon. This goes well with the choice of phenomenology as our scientific theoretical approach, where one gains insight into and understand the perspectives of each individual (Kvale & Brinkmann, 2015: 49). The semi-structured interview allows the interview person to talk more freely about the topic compared to the structured interview, but it also ensures that we cover the relevant themes about intellectual disabilities and PFPID (Kvale & Brinkmann, 2015: 35, 49-50).

#### *Selection of interview persons*

As mentioned before PFPID is a well-established NGO in Nepal working with intellectual disabilities. Therefore, we found it relevant to do some interviews with the staff of PFPID to gain an understanding about the life conditions of people with intellectual disabilities, and what PFPID does to improve these. Therefore, we have used the method called convenience sampling (Andersen & Hansen, 2012: 163-164). By interviewing the staff of PFPID we found that the life conditions are worse in the rural areas compared to the cities. Based on this we decided to do some interviews with parents of intellectually disabled living in rural areas. The president of PFPID contacted one of their member organisations that helped us arrange a trip to the Nepalese village Chautara. A contact from the member organisation choose six interview persons based on our problem field. This way of selecting interview persons is defined as the snowball sampling (Andersen & Hansen, 2012:164). With these interviews we achieved a wider understanding of the challenges they meet in daily life.

Table 1. Staff of PFPID

Pseudonym	Duration of interview	Function	Annex no.
Chaha	35 min	Volunteer	5
Alina	35 min	Volunteer	5
Binsa	18 min	Field officer	6

Dhonu	27 min	Program officer	7
Faneel	32 min	President of PFPID	8

Table 2. Parents

Pseudonym	Duration of interview	Relation	Child	Annex no.
Amita	44 min	Mother	Female - 15 years old	9
Nisu	26 min	Mother	Female - 10 years old	10
Liv	16 min	Mother	Male - 25 years old	11
Sona	9 min	Mother	Female - 10 years old	12
Ansu	55 min	Mother/ grandmother	Male - 44 years old Female - 31 years old Male - 15 years old Male - 12 years old	13
Prati	26 min	Mother	Female - 7 years old	14

### *Preparation of interview guides*

As mentioned before, we have had an inductive approach, which means that we based our interview guides upon open questions. This complemented our phenomenological approach because it made it possible for our interview persons to speak freely about their personal experiences and perceptions. However, we tried to make the questions very specific and have used an understandable level of English due to linguistic barriers. Regarding the structure of the interview guides we chose the funnel approach. This means that we started out asking background questions and afterwards more specifically about thematics, which makes it possible to answer our thesis statement (Kvale & Brinkmann, 2015: 185). The intention of starting with background questions is to create an open dialog and safe atmosphere, which makes the interview persons more likely to answer the following questions.

As we had two different groups of interview persons, the staff of PFPID and the parents, we created two interview guides (cf. annex no. 1, 2). The staff of PFPID informed us about the low level of education and language properties in rural areas, which is why we created concise questions and reduced the number of questions for the parents. To ensure that the questions were understandable for the parents we drafted the interview guide together with the staff of PFPID.

### *Conducting interviews*

All interviews were conducted on the interview persons premises. The staff members of PFPID were interviewed at the office at self-chosen times to create a safe atmosphere except for Faneel, the President of PFPID (Kvale & Brinkmann, 2015: 184). We decided to interview Faneel at his home after office hours, because he is a busy man and therefore, he is often out of office. We had the opportunity to do this, because we were staying with him and his family during our internship at PFPID. When conducting the interviews of the staff we started out by briefing the interview persons about their anonymity and that the interview would be recorded, as well as their right not to answer questions if they found them to be intimidating. This was done to make them feel secure and hopefully speak more freely (Kvale & Brinkmann, 2015: 183). At the end of the interviews we did a debriefing to give them the opportunity to add more and thanked them for their time.

During the interviews with the parents we used an interpreter, because as mentioned before the English level of the parents were non existing. The interpreter that we used is a 28-year-old Nepalese woman, who is studying social work in Kathmandu. She was chosen by the president of PFPID as she is a former volunteer at the NFD-N, where he also works. In the beginning of the interviews the interpreter briefed the parents about the purpose of the interview and some general information about us in Nepali. During the interviews we asked the questions in English directly to the interview person and the interpreter translated these into Nepali. Subsequently the interview persons respond were translated into English, so that we could react upon their answers.

The contact person from the member organisation arranged where the interviews should take place, based on what would be most convenient for the parents. We did two of the interviews at the local day-care centre, as one of the mothers works there as a helper and another one where there to deliver her child while we were there. To avoid disturbances, we went to the kitchen of the day-care centre to do the interviews. The following two interviews were conducted in a local fabric shop owned by one of the parents. However, this location was not ideal because of noise from the street, but we decided to complete the interviews anyway,

as the parents preferred this location. We did the last two interviews in a local house owned by one of the parents, which created a safe atmosphere. Even though some of the locations were not optimal we still decided to perform the interviews, as we prioritized to accommodate the wishes of the parents. The interviews with the parents were also recorded to secure the data (Kvale & Brinkmann, 2015: 236-237).

All three of us were present during the interviews, where one acted as the interviewer and the others as observers. Furthermore, the observers also asked follow-up questions or helped by rephrasing questions that the interview persons did not understand.

### **3.5 Observations**

We conducted participating observations in the village Chautara on October 16th, 2019. The observations took place in the local day-care centre and during the interviews. By doing participating observations it is possible to gain knowledge about behavioural patterns and social relations among our interview persons. This method also gives us the opportunity to get an adequate understanding of the Nepalese culture, but also the daily life of the parents and their children, which corresponds well with the phenomenological approach. Another advantage of doing participating observations is that it makes it possible for us to build a trustworthy relation to the interview persons. The established trust makes it easier for the parents to open up about personal experiences. It has not been possible for us to only take the role as observers because we felt that our presence affected the dynamics. This was caused by the fact that we look different, and therefore we received a lot of attention (Løngren & Sørensen, 1993: 62-65).

### **3.6 Data processing**

Before the transcription process we created a transcription-key to secure the uniformity of the transcriptions (Annex no. 3). The person who conducted the interview were also the one who did the transcription, because they had the best understanding of interview situation (Kvale & Brinkmann, 2015: 236). In relation to the transcriptions we have also decided to omit uncomprehending speech, which can be caused by language barriers.

We have chosen an open and data-based coding process according to our inductive and phenomenological approach (Brinkmann & Tanggaard 2015: 241). This means that we did not create categories before the coding process, as we wanted the perspectives of our interview persons to be in focus (Kvale & Brinkmann, 2015: 263). Subsequently we began to categorize our data, which is defined as axial coding (Hutchison, Johnston & Brockon, 2010: 291). Moreover, we did selective coding by assembling the categories from the process of

axial which lead to some main-categories (Corbin & Strauss, 1990: 15-16). We ended up with the following eight main-categories: Culture & traditions, The view of society, Life conditions of PWID, Relation to government, PFPID, Caretakers, Development and Inclusion (annex no. 4). These main-categories are the foundation of our analysis.

### **3.7 Validity**

The biggest challenge in relation to the validity of this research is the linguistic barriers. We have experienced miscommunication because English is neither our nor their first language. The consequences of this miscommunication are loss of data and possible incorrect data. For example, we experienced that the interview persons sometimes did not understand our questions, which affected our understanding of their answers. This was often caused by strong dialects. In these situations, we reformulated our questions and asked follow-up questions to increase the level of validity. We have not used follow-up questions consistently because this would ruin the flow and create insecurity among the interview persons. In some cases, we experienced that the staff of PFPID based their answers on the policy of the organization instead of their individual views. This could be caused by the fact that they wanted to appear politically correct, as they may have had an economical interest in making the organization seem valid. This has mainly been expressed by the staff being overly positive about the work of PFPID. Moreover, they gave unilateral explanations in relation to how the organisation can improve PWID' life conditions and achieve inclusion for all PWID. We have been aware of this by being critical towards their answers in the analysis.

During the interviews with the parents, we also experienced some circumstances that affected the validity. The locations and surroundings during the interviews had a negative impact on the interview situation. For example, we experienced noise from the road, which made it difficult to hear the answers of the interview person and respond to these. Moreover, we experienced that a lot of outsiders were present during the interview situations. This seemed disruptive to the interview person, the interpreter and us. The outsiders tried to participate in the interviews in Nepali, which could have affected the answers of the interview person and made them unfocused.

The use of an interpreter also affected the validity as some of the data may got lost in the translation. This is caused by her lack of English skills and the fact that she compresses the answers from the interview persons. The interpreter has been the link between us and the parents, which made it difficult for us to control the interview situation. The interpreters cultural understanding can affect her translation, because some of the cultural aspects may appear as common sense to her. However, her cultural understanding can also be an

advantage as she has a preunderstanding of the interview person's cultural background. There her cultural understanding can increase and decrease the validity. Her local appearance and her ability to speak Nepali creates trust between her and the interview persons (Kvale & Brinkmann, 2015: 198-199).

To create a good relationship with the parents and build up trust we acted open minded towards the parents and their intellectually disabled children. For example, we socialized with the parents and interacted with the children before and after the interviews. Moreover, we tried to act politely by saying yes to tea when offered, which made the atmosphere more casual. By creating a good relation to the interview persons, they are more likely to tell about their personal experiences and give honest answers, which have affected the validity of our data.

Regarding the collection of our data we have experienced some challenges which has had a negative effect on the validity. Taking the circumstances into account it has been difficult for us to decrease these biases because of the cultural differences. However, we have tried to be aware of the consequences of these.

## 4. Theory

In the following section we will introduce our chosen theory, which is based on our empirical data. We will present the forms of capitals by Bourdieu and how this theory will be used to assess PWID' life conditions. Furthermore, we will use Honneth's theory about recognition to examine PWID' recognition in society and their opportunity of inclusion. These theoretical concepts will later on be used in the analysis according to answering our thesis statement.

### 4.1 The forms of capital by Bourdieu

Pierre Bourdieu operates with four different forms of capitals, which is an expression of the individuals' amount of resources that are considered legitimate within the field. The four capitals consist of economical capital, cultural capital, social capital and symbolic capital. The economical capital is defined by the individuals amount of money and other material resources (Bourdieu, 1986: 252). Cultural capital can exist in three different forms; the embodied state, the objectified state and the institutionalized state. In this project we will especially make use of the institutionalized cultural capital. This form of cultural capital is perceived as the education of the individual (Bourdieu, 1986: 243). Furthermore, social capital is an expression of the resources of the individual in relation to network. A high level of social capital can both consist of a wide network or strong relationships with fewer people (Bourdieu, 1986: 248-249). The symbolic form of capital is the total quantity of the aforementioned capitals, as these can be converted into symbolic capital, if they are considered legitimate within the field. If the individual has a legitimate composition of capitals, they will achieve recognition and honour, which is characteristic for a high level of symbolic capital. A recognized resource composition can improve the opportunities of the individual within the field (Andersen & Kaspersen, 2013: 372).

We find it relevant to make use of Bourdieu's capitals, as these are essential for assessing the life conditions of PWID and their parents. More specifically, we have assessed their amount of capital within each form of capital, which has given us an impression of their total amount of capital, as well as resources within the field. The forms of capitals are also used to examine how PFPID is trying to improve the life conditions of PWID by increasing their amount of capitals. Overall this gives us an impression of their challenges in daily life and their opportunities in society.

#### **4.2 Honneth's theory of recognition**

Axel Honneth works with the concept of recognition, which he differentiates into three recognition spheres: the private sphere, the legal sphere and the solidarity sphere. In the private sphere the individual achieves recognition from their family and other close relations. The recognition in the private sphere is expressed by love and intimacy. In the legal sphere the recognition is gained through universal rights, which makes the individual feel like an equal member of society. The recognition in the solidarity sphere is obtained from minor communities, where the individual is recognized for their contributions to the community. If the individual is lacking recognition in the spheres it will not be able to achieve a good life, as recognition in all the spheres is necessary (Honneth, 2006: 11-13).

Honneth's theory of recognition will be used to examine PWID and their parents' level of recognition in the different spheres and society. In relation to our project we define the private sphere as PWID' and their parents' relationship to close family. To examine PWID' and their parents' level of recognition in the legal sphere we primarily focus on the rights and support given by the Nepalese government. This gives an impression as to what extent the Nepalese government recognize PWID and their parents. Furthermore, we define the solidarity sphere as minor communities, where PWID have the opportunity to gain recognition based on their abilities. Based on the above we will evaluate PWID' life conditions and their opportunities of inclusion in society.

We will primarily use the theory of the different capital forms to explain PWID' daily life challenge and their opportunities in society. Moreover, we will make use of Honneth's recognition theory in relation to express the discrimination towards PWID and how it affects their opportunity of full inclusion in society. These theories complement each other as there is a connection between the PWID' level of recognition and their life conditions.

## 5. Empirical results

In this section we will present the most essential empirical findings. First there will be an introduction of our interview persons. First of all, we will introduce the staff of PFPID and their relation to the organisation, and subsequently introduce the parents of PWID to get an understanding of their life situation. Furthermore, we will elaborate the following thematics in relation to our empirical results; Life conditions, Discrimination from society, Causal explanation of condition, PFPID.

### 5.1 Introduction to interview persons

#### *Introduction to the staff of PFPID*

Chaha and Alina are both studying social work and as a part of their education, they are volunteering at PFPID twice a week. Binsa has been working as a field officer at PFPID for one and a half year, which means that she mainly visits the day-care centres and is in contact with the member organizations. Dhonu is the program officer of PFPID, which means that he primarily is in charge of organizing training programs for PWIDs and their parents. Faneel is the president of PFPID and therefore he acts as the primary spokesperson for the organization.

#### *Introduction to the parents*

Amita has a daughter who is intellectually disabled and 15 years old. Besides her she has five other daughters. Amita does not have a job, which means that she is a housewife and mostly spends her time taking care of her intellectually disabled daughter. Nisu who is the mother of a 10-year-old intellectually disabled girl and a six-year-old boy, spend her daytime working as a helper at the day-care centre in the village Chautara. Liv has a 25-year-old son, who is intellectually disabled. Besides him she has two other children. Her and her husband runs a fabric shop in Chautara, which means that the whole family is taking care of her son, but mainly he remains in the shop with his parents. Sona is the mother of a 10-year-old intellectually disabled girl, and besides her she has two sons. In the daytime she works as a teacher, and therefore her daughter spends most of her time in the local day-care centre of Chautara. However, when her daughter is not in the day-care centre, she is the primary caretaker. Ansu has a 44-year-old intellectually disabled son, who is married to another intellectually disabled woman and together they have two intellectually disabled sons in the age of 12 and 15 years. Ansu spends most of her time doing household work and taking care of her family. Prati is the mother of a seven-year-old intellectually disabled girl and besides her she has a two-year-old son. Prati is also a housewife and the only one who takes care of her children. All the parents that we have

interviewed are living in the village Chautara and also it is characteristic for them that they do not have an education besides the teacher Sona.

## 5.2 Life conditions

The life conditions of PWID are different from the rest of the Nepalese population. This is expressed by the staff of PFPIID as PWID experiences many challenges in their daily life and are often not able to take care of themselves. One of these challenges is stated by Dhonu: "In Nepal basically PWID are the poorest of the poor and most important these days there is a poverty circle". This is often caused by the fact that it is not possible for both of the parents to work, because it is necessary that at least one of them takes care of their disabled child, which means that they only have one income. In some cases, both of the parents are forced to work to cover their basic needs, which means that they chain their child in the home while they are at work. In some areas it is possible for parents to have their child taken care of in a day-care centre, however this is costly. In the day-care centres there is also a resource issue, because there are not enough caretakers compared to the number of children. This is shown by the fact that the caretakers also bind the children to chairs, when they are not able to keep an eye on all the children (annex no. 15).

To improve the parent's economic situation the government has made a card-system where the families are assigned economic support based on the PWID's condition. In theory every intellectual disabled have the right to get a card but in practice only "50-60 percent with intellectual disabilities have ID card" according to Faneel. This is also exemplified in the interviews with the parents where only four out of six families get economical support from the card-system. Even though the government is trying to improve PWID' economic situation they still have economic challenges.

### *"Take her to the special school"*

The government is also trying to improve the life conditions of PWID by giving them the right to be included in the mainstream schools. The mothers of the children that we interviewed expressed that their childrens' schooling in the mainstream school has been a bad experience. Prati explains that her "daughter doesn't study. The letters does not go in her head. I forcefully send her to the boarding school, but the teacher complained that she opens her clothes and sleeps naked. So, I can't take her in the school". Among our interview persons some of the parents have chosen to take their child out of the mainstream school because of these bad experiences, while other parents have gotten their child kicked out of school. The consequences of this is that the children do not get an education, which makes it difficult for them to improve their life conditions.

The mainstream schools do not recognize their capabilities but perceive them as a burden. This is exemplified by Alina: "they have potential, but they cannot show their full potential. People are like "you are disabled, and you are limited of what you can do"". This is the reason why they are not included in the school system".

In general, the children of the parents that we interviewed do not have a very wide social network, which is caused by the fact that they do not have the opportunity to socialize with others in educational and occupational contexts. However, they often have a strong relation to their family, or at least to their mothers as they are the ones taking care of them. For some of the children it is also difficult to form relationships, because of their condition. Sona mentions that her daughter does not even recognize her, which exemplifies how difficult it can be for them.

### **5.3 Discrimination from society**

The staff of PFPID expresses that PWID are a marginalized group, who experiences a lot of discrimination. Dhonu explains that some parents of PWID do not bring their children to social events in public because they are ashamed and afraid of other people's reaction. However, the discrimination also applies within the family as some family members are not willing to accept the intellectually disabled. This is the case in Nisus family, which she explains as:

"My relatives and neighbours used to say that there is no one like her in the whole world. "Why did you give birth to this kind of girl?". My parents also used to say, "take good care of her and give her treatment and make her nice". My relatives say that "in all these years we do not have children like this, why do you have?"".

Another example of lacking accept from family members is shown in the interview with Prati. Her father in law works as a government officer but he denies the condition of her child. Therefore, he will not provide her with economic support from the card-system even though he has the possibility. When it comes to the way other people look at PWID our interview persons have different experiences. Ansu shares how people have been taking advantage of her intellectually disabled grandsons:

"My grandchildren goes to the school and other people will tell them to buy something like pens, chocolate or noodles and they go out of the school. The teachers will say "why you are out of the school?", and the one who made them go, they say "we haven't sent". So, they (grandsons) will get beatings. They (grandsons) are getting ignorance from the teachers".

Binsa has another perception of how people look at PWID. She explains that people feel pity for PWID, because they believe that they cannot take care of themselves. This shows that there are also some negative attitudes towards PWID, however the majority of the parents did not have any bad experiences in relation to how other people react to their children. Though the parents still worry about how others will treat their children, when they are not around.

#### **5.4 Causal explanation of condition**

When it comes to the explanation of why the children are intellectually disabled there are various perspectives. Dhonu explains how society often links the condition of PWID to the behaviour of the parents:

“They are the result of the parent’s worst things in previous life. They do not link it to medical reasons or other things like that, so maybe there have been bad activities in previous life, or they had done some bad karma in their previous life. That is the reason why they are getting this child”.

Prati expresses that she has experienced this as her relatives believe that the condition of her child is caused by a sin in a former life committed by her. The belief that the condition of PWID is caused by a sin in a former life committed by the parents is related to the fact that they believe in karma and reincarnation. Besides this we also experienced that some of our interview persons linked the condition of their child to black magic. Amita exemplifies this:

“When my daughter was one-and-a-half-year-old some people did the black magic to her. So, in one month she was sick in a bed unconscious, so we took her to the magician to do the rituals. They worshipped all the Gods and in one month she was in the magician home and then she was worshipped. My thought is that it is because of the black magic”.

These two cases illustrate how sin and black magic becomes explanatory factors in relation to why their children are intellectually disabled. However, Ansu has another perspective as she believes that her son is intellectually disabled because he ate soil at the age of three. Nisu explains that the condition of her child is caused by the fact that she did not cry at birth, which is the reason why she think that her daughter’s brain does not work properly. She defines this as a general explanation of intellectual disabilities.

## 5.5 PFPID

As mentioned before PFPID is an NGO that works to improve the life conditions of PWID. Dhonu describes PFPID as “an organisation of parents so they can speak for their children who cannot speak for themselves”. The primary work of PFPID is advocacy and lobbying, which is practically done by trying to make sure that the Nepalese government complies with the policies concerning PWID. By advocating and lobbying PFPID attempts to improve PWID’s recognition by cooperating with the government. Dhonu is explaining how PFPID maintains a good relation to the government:

“They are invited to different programs of PFPID. PFPID is also called for different programs and while drafting different policies we have a consulting meeting where PFPID is invited. Here we share our issues that needs to be addressed. We provide feedback to the government and sometimes they also funds PFPID to implement some kind of activities for PWID”

Another way of improving PWID’ life conditions is by providing training programs to the PWID and their parents. These trainings provide knowledge about the rights and opportunities of PWID and their parents in society. The programs seek to develop their advocacy skills, so that they can advocate for themselves. The way in which PWID and their parents are getting these skills are through practically oriented teaching. Through these training programs PWID and their parents also get to socialize with each other and share experiences. Dhonu expresses some of the positive outcomes of these trainings:

“It is important that the children meet each other in different types of training, so that they can have pair support with each other and not remain isolated. Their parents also meet with each other and share how they feel and their sorrows and learn from each other, so I think it is mostly trainings and workshops that PFPID does to let PWID know about their rights”.

Besides the trainings PFPID also produces and provides easy to learn material for PWID. The material is often books with a lot of pictures and short sentences with the purpose of teaching PWID about basic life skills such as how to dress and eat properly. The intention with the easy-to-learn material is to develop their ability to take care of themselves.

### *Development*

According to PFPID there has been a positive development in the way society perceives PWID. However, the parents that we interviewed expressed that they and their intellectually disabled child still experience discrimination from others. Although the staff of PFPID are positive about this development, Dhonu expresses that it is a long-lasting process to change the mindset of society towards PWID:

“My personal opinion is that it is very difficult and takes a long period of time. It is the cultural thing and a social thing that has been for ages, so it takes time to change. The mindset do not change in a click, right? So, it takes time but eventually it will happen, we are positive on that”.

Even though there has been a positive development in the way society views PWID according to the staff of PFPID, the parents point out that there is still room for improvement especially when it comes to facilities and services. These are also essential for improving their life conditions according to the parents. For example, they would like special schools with good facilities for their intellectually disabled children and more economic support.

### *Humanity is diversity*

As mentioned before PFPID's main focus is inclusion of PWID in society. However, Chaha expresses that it can be difficult to include all PWID: “Because PWID they have different form of severeness. Not everyone can be included. I think the ones with minor disabilities can be, but the ones with severe disabilities can be difficult”. Faneel elaborates this by saying:

“The human rights is the same for every person, but humanity is diversity. Every person they have special needs. Not the same needs for every person. I think PWID they are not accepted for their special needs”.

To achieve inclusion for all PWID it is necessary for society to recognize their special needs. Faneel indicates that PFPD is aware of the importance of recognition when it comes to inclusion, as all their strategies are about PWID being recognized by the society, which improves their life condition.

## 6. Analysis

In the following section we will use our theoretical framework to analyse and interpret our empirical results. The structure of our analysis is based on the thematics from our empirical results. Finally, we will summarize the analysis by constructing a model that illustrates the cause for the life conditions of PWID.

### 6.1 Life conditions

As mentioned before PWID experience a lot of challenges that affects their life conditions. They are described as “the poorest of poor” in Nepal, which is often caused by the fact that the parents of PWID only have one income, as one of them need to take care of the child. This indicates that they have a low level of economical capital. However, some families have the option to bring their child to a day-care centre in the daytime, which gives both of the parents the opportunity to work. Having their child in a day-care centre requires a certain level of economical capital, which makes it impossible for some families. Even though both of the parents have one income they still have a low level of economical capital as the second income will often be used to pay for the day-care centre. This means that the families are kept in a poverty-circle as it is costly to have their child in the day-care centre but also to have one of the parents taking care of the child. It is hard for the families to break with the poverty-circle, as they cannot improve their level of economical capital. Nevertheless, the Nepalese government is trying increase PWID and their parents’ level of economical capital through the card-system. This shows that the government recognise them judicially, but not every intellectual disabled achieves recognition in the legal sphere, because as mentioned earlier not every PWID are assigned a card.

Besides the card-system the Government is trying to improve PWID’s institutionalized cultural capital by recognizing them in the legal sphere as they have given them the right to be included in the school system. In spite of the right to equal education PWID do not feel recognized in the mainstream school, which means that many PWID do not go to school. Therefore, the government is unable to implement the educational policy for PWID. This means that the recognition in the legal sphere from the government becomes insignificant when it comes to improving the life conditions of PWID. The consequences of this is that they do not get an education, which means that they do not have the opportunity to improve their institutionalized cultural capital. The fact that PWID are not recognized in the school system means that they are lacking recognition in the solidarity sphere. Moreover, the lack of schooling means that PWID do not have the opportunity to form social relations, which is one of the reasons why PWID neither have a wide or a strong network. This

indicates that they have a low level of social capital. Furthermore, it can be difficult for PWID to increase their social capital because in some cases their condition can make it challenging to interact with others.

Overall PWID have a low level of the capitals, which means that their resource composition is not considered legitimate within field. This means that they are lacking symbolic capital, and therefore it is difficult for them to achieve recognition and honour.

## **6.2 Discrimination from society**

As mentioned above PWID experience discrimination in different situations. Moreover, the discrimination also applies in the private sphere where some family members are not willing to accept the intellectually disabled. This is exemplified in the aforementioned cases of Nisu and Prati who are lacking recognition in the private sphere. In relation to the solidarity sphere PWID are experiencing different levels of discrimination from society. For example, Ansu expresses how her grandsons have experienced discrimination from classmates however most of the parents explained that they have not experienced discrimination from others. These cases indicate that PWID experiences different levels of recognition in the solidarity sphere because there are different views on their role in society and how they can contribute to the community.

By extension most PWID have been stigmatized because they deviate from what society define as normality. Based on their condition PWID are exposed to stigmatization as their disability affects their personality and physical appearance, which makes them deviate from the normal. Most PWID's stigma is visible which means that society often responds to them in a negative way. The stigmatization that the parents and PWID experiences is caused by the fact that society is categorizing them. PWID are being categorized as abnormal while the parents are being categorized based on their children's categorization. PWID and their parents are treated according to how society categorize them. The way society treats them affects their self-understanding and how they act in society. Therefore, it is difficult for PWID and their parents to break with their stigmatization, because they themselves are responding to their categorization and therefore participating in the reproduction of it. According to the staff of PFPID this discrimination towards PWID and their parents is caused by a general lack of knowledge and education in society within the field.

## **6.3 Causal explanation of condition**

Lack of knowledge and education also affects the parent's explanation of their children's condition, which is shown by their non-scientific explanations instead of a medical explanation. This is especially caused by the

fact that the majority of the parents do not have an education, and therefore they are not very well informed in general. This means that they seek explanation elsewhere, which means that culture and belief becomes the explanatory factors of their children's' condition. These beliefs, such as black magic and sin in a former life, are rooted in their culture and traditions, which makes them appear as common sense to the parents. As these non-scientific explanations become a part of their common sense, they do not question them, which means that these beliefs are being reproduced. This makes it difficult for them to accept scientific explanations, as their believe in reincarnation and karma means that they seek a connection between previous actions and consequences. Most of the non-scientific explanations are based on a specific incident, such as the children eating soil in their early childhood. In contrast, scientific explanations are often based on biological reasons, such as the child being born with an extra chromosome which is not a consequence of a previous act. Overall this means that the parent's culture and belief in reincarnation and karma affects the way they perceive their children. This cultural mindset also applies in society, which means that the discrimination towards PWID is being maintained.

#### **6.4 PFPID**

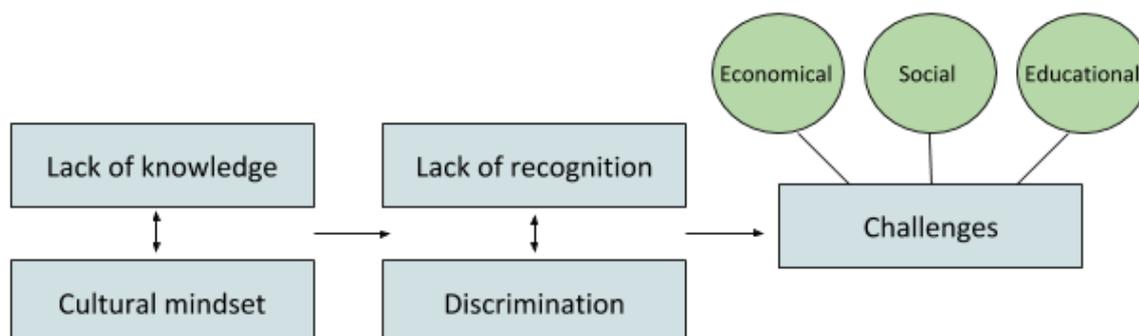
As mentioned before the primary work of PFPID is advocating and lobbying, and by doing that PFPID attempts to improve PWID' recognition in the legal sphere. This is done by cooperating with the government. Another way of improving PWID' recognition in the legal sphere is by providing training programs to the PWID and their parents, as the parents through these trainings get knowledge about their rights and advocacy skills. This means that PWID and their parents can increase their level of institutionalized cultural capital within the field, as they now know how to make use of their rights and therefore improve their life condition. Another benefit of the trainings is that PWID and their parents get the opportunity to socialize with each other. This shows that the training also increases PWID and their parent's social capital, because they expand their network and develop strong relations as they can identify with the other participants and learn from each other's experiences. Through the trainings PWID and their parents gain a feeling of fellowship and therefore they experience recognition in the solidarity sphere. The recognition is caused by the feeling of appreciation and acceptance. As mentioned before PFPID also provides easy-to-learn material for PWID, which also increases their level of institutionalized cultural capital, and therefore they get more opportunities within the field, as they become more independent.

PFPID mentions the positive development in how society views PWID. This indicates that there has been a positive change in how society categorizes PWID. However, there is still a long way to complete inclusion of all PWID. To achieve inclusion for all PWID it is necessary for society to recognize their special needs. Amongst

these are the need of recognition in the spheres: the legal, the private and the solidarity sphere. Recognition in all of the spheres is necessary for a good life and to feel included in society. As mentioned before most of the PWID are lacking recognition in at least one of these spheres, which means that their quality of life degrades. Therefore, it is necessary for PFPID to figure out how to increase PWID' recognition in the different spheres, so that they can feel included in society.

## 6.5 Summary of analysis

In the model below we have tried to summarize as well as illustrate our analytical main points. In Nepal there is a cultural mindset, that are based on religious beliefs in reincarnation and karma. Besides these beliefs it is also a general issue that the Nepalese society are lacking knowledge about PWID. This cultural mindset and lack of knowledge in society affects the attitude towards PWID and causes discrimination, which is expressed by PWID' lack of recognition in the different spheres. The discrimination and lack of recognition leads to a lot of challenges in the daily life of PWID, such as economic, social and educational challenges. These challenges affect their life conditions, and therefore it is difficult to improve the life conditions of PWID. To improve the life conditions of PWID it is necessary to change the cultural mindset radically and raise awareness about PWID in Nepal.



## 7. Discussion

In this section we will discuss our empirical results by comparing these to the literature from the literature review. Moreover, we will focus on presenting differences and similarities between our analytical findings and the literature. Within this section the universalism of the human rights will be discussed in relation to PWID in Nepal.

According to our empirical results PWID and their families are poor, and to cover their basic needs both parents are often forced to work. This means that there is no one home to take care of their intellectually disabled child, and therefore they are forced to bind them. NFD-N describes that this is a common issue due to lack of resources within the families with intellectually disabled children. In our research it is shown that the government is trying to improve PWID economic situation by providing them a card-system. However, our results also show that it has not been implemented properly, as it is far from every intellectually disabled who is provided a card. It is stated by Crishna and Prajapati that it is a general issue that legislations are not being implemented sufficiently in Nepal.

Another issue in relation to the life conditions of PWID is that they are lacking education, because the mainstream schools do not have the facilities to meet their special needs. Research from the Population Census also shows that only approximately half of PWID are attempting schools, and this is among other issues caused by the fact that the schools cannot provide them with the needed facilities. The parents that we interviewed expressed that their children experienced discrimination from both other students and teachers when they attempted school, and this is also a widespread issue in Nepal according to Brandt. The research by Crishna and Prajapati shows that intellectually disabled children do not improve the needed skills, when they do not attempt school. However, some of the parents that we interviewed expressed that they chose to take their intellectually disabled child out of school, as they considered that they did not learn what they were supposed to, because of lack of facilities and discrimination from others. Our study also shows that PWID and their parents experience discrimination from society and within their families. According to Brandt, Crishna and Prajapati this is the main obstacle in relation to improving the life conditions of PWID and not the lack of implemented legislations. However, the parents that we interviewed expressed that better facilities such as more economical support would help to improve their life conditions.

According to the staff of PFPID the discrimination that PWID experience is mainly caused by lack of knowledge and education. This is also the case according to Crishna and Prajapati, who also describes that religion

prevents society from accepting them. We also found that culture and religious beliefs has an impact on how the parents of PWID explains their children's condition, as they use these beliefs as explanatory factors.

In our research we found that PWID do not have equal rights in Nepal, which is mainly caused by the attitude towards them. That is critical as it is a part of the Universal Declaration of Human Rights that all human beings are equal. This shows that the Human Rights are not universal in Nepal. In general, it is difficult to universalize the Human rights as they are based on western values according to Baylis, Smith and Owens. Niezen is also critical towards the universalism of the human right as they do not account for diverse life conditions. In relation to this it can be argued whether PFPID's overall goal about inclusion for all PWID is sustainable. This is caused by the fact that PFPID works upon the belief that all PWID are already equal human beings. However, our research indicates that the Nepalese society do not recognize them as equals. As mentioned before the Nepalese government has adopted different policies to improve the life conditions of PWID. In reality these policies do not make a big difference in relation to improving their life conditions because they have not been implemented properly. When people in Nepal discriminates PWID and hereby violates their human rights they are not held accountable for their actions, and therefore the human rights become an illusion. PFPID is trying to make these policies a reality by advocating, to make sure that the rights of PWID are being complied by the government. To advocate for a minority's rights is defined as the purpose of NGOs by Nickel.

Both our research and the literature indicate that the view from society is the biggest obstacle in relation to improve the life conditions of PWID. This view is mainly caused by their cultural mindset and lack of knowledge in relation to PWID. Therefore, PFPID should consider having more focus on fighting the discrimination and changing the mindset towards PWID. Crishna and Prajapati propose that this can be done by raising awareness about PWID, so that society can learn how to value them.

## **8. Conclusion and elaborating perspectives**

### **8.1 Conclusion**

In this project we have examined the life conditions of PWID in Nepal by looking into the different challenges that they face, and moreover what PFPID does to improve their life conditions. To examine this, we have used an inductive and phenomenological approach. This is done by conducting semi-structured interviews, which gave us an understanding of the interview person's experiences in relation to the life challenges that PWID face and the work of PFPID. Furthermore, we did participating observations to get an understanding of the Nepalese culture and the everyday life of PWID and their families.

Based on our study we have come to the following conclusion. In general, PWID in Nepal experience a lot of different challenges in their daily life. This is exemplified by their poor economic situation, lack of education and the absence of social relations. This means that they are lacking recognition in the private sphere, the legal sphere and the solidarity sphere, which is caused by discrimination and stigmatization from society. The discrimination and stigmatization emanate from the cultural mindset and lack of knowledge in Nepal, which has a negative impact on others attitude towards PWID. In relation to the daily life challenges that PWID experience the NGO PFPID seeks to improve their life conditions by advocating and lobbying. Moreover, they are trying to increase their recognition in the spheres to achieve full inclusion for all PWID. This is primarily done by providing training programs for PWID and their parents.

In our research we have found out that the biggest obstacle in relation to improving PWID' life conditions are the cultural mindset and the lack of knowledge in Nepal. The cultural mindset is mainly based on cultural and religious beliefs such as reincarnation and karma. It is difficult to change the Nepalese mindset as it is deeply rooted in their culture, and therefore it appears as common sense to the Nepalese people. Therefore, it is challenging for PFPID to improve the life conditions of PWID and to gain inclusion for all PWID. However, an increased focus on raising awareness and knowledge about PWID could be a solution in relation to improving the life conditions of PWID, as this could make the Nepalese society value and accept PWID.

### **8.2 Elaborating perspectives**

Our study is based on semi-structured interviews with the staff of PFPID and parents of PWID living in rural areas. This means that we have mainly focused on examine the life conditions of PWID in rural areas. For future research it could be interesting to compare the life conditions of PWID within the rural areas and the urban areas. This could be done by interviewing parents of PWID living in urban areas and observations.

Furthermore, it could be interesting to examine the discourse towards PWID, by having a social constructivist approach, which could give a better understanding of how the attitude towards PWID is constructed and reproduced in society. In relation to this it could be meaningful to do focus group interviews, as these would give an impression of how the discourse is being created in interactions with others.

## 9. Bibliography

Andersen, H. & Kaspersen, L. B. (2013). *Klassisk og moderne samfundsteori*. Hans Reitzels Forlag, Kbh.

Andersen, L. & Hansen, K. (2012). *Metoder i statskundskab*. Hans Reitzels Forlag, Kbh.

Baylis, J., Smith, S. & Owens, P. (2011). *The Globalization of World Politics*. Oxford University Press.

Berger, P. & Luckmann, T. (1972). *Den samfundsskabte virkelighed*. Vintage books.

Bourdieu, P. (1986). *The forms of Capital*. In: Richardsen, J. *Handbook of Theory and Research for the Sociology of Education*. Westport, CT: Greenwood.

Brandt, Lina. (2015). *The Inclusiveness of Society for Children with Disability in Nepal. A CRITICAL ANALYSIS OF THE CONCEPTUALIZATION OF DISABILITY IN POLICY AND PRACTICE*. Maastricht University.

Brinkmann, S. & Tanggaard, L. (2015). *Kvalitative metoder – en grundbog*. Hans Reitzels Forlag, Kbh.

Corbin, J. & Strauss, A. (1990). *Grounded Theory Research: Procedures, Canons and Evaluative Criteria*. *Qualitative Sociology*, vol. 13.

Crishna, B. & Prajapati, S. B. (2008). *Comparative Policy Brief. Status of Intellectual Disabilities in Nepal*. *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 5 No. 2.

Eide, A. H., Neupane, S. & Hem, K. G. (2016). *Living conditions among people with disability in Nepal*. SINTEF Technology and Society, Department of Health Research.

Geertz, C. (1973). *Religion as a Cultural System*. Fontana Press.

Goffman, E. (2009). *Stigma. Om afvigerens sociale identitet*. Samfundslitteratur.

Government of Nepal. (2014). *Population Monograph of Nepal. Volume II (Social Demography)*. Central Bureau of Statistics.

Hacking, I. (1995). *The looping effects of human kinds*. In: Sperber, D., Premack, D. & Premack, A. J. (Eds). *Causal cognition: A multidisciplinary debate*. Oxford: Clarendon Press.

Honneth, A. (2006). *Kamp om anerkendelse: Social konflikters moralske grammatik*. Hans Reitzels Forlag, Kbh.

Juul, S. (2012). *Fænomenologi*. In: Juul, S. & Pedersen, K. B. (red.). *Samfundsvidenskabernes videnskabsteori - en indføring*. Hans Reitzels Forlag, Kbh.

Hutchison, A. J., Johnston, L. H. & Brockon, L. D. (2010). *Using QSR-NVivo to facilitate the development of a grounded theory projekt: an account of a worked example*. *International Journal of Social Research Methodology* 13 (4).

Kanter, A. S. (2014). *The Development of Disability Rights Under International Law: From Charity to Human Rights*. Routledge Press.

Kristiansen, S. (2010). *Kvalitative analyseredskaber*. I Brinkmann, S. & Tanggaard, L.: *Kvalitative metoder - En grundbog*. Hans Reitzels Forlag, Kbh.

Kvale, S. & Brinkmann, S. (2015). *Interview - det kvalitative forskningsinterview som håndværk*. Hans Reitzels Forlag, Kbh.

Løngren, H. & Sørensen, B. H. (1993). Deltagerobservation. I: *Mediekultur* no. 21.

Møller-Kristensen, F. (2017). *Nepal (Religion)*. I: *Den Store Danske*, Gyldendal: [http://denstoredanske.dk/Sprog%2c\\_religion\\_og\\_filosofi/Religion\\_og\\_mystik/Indiske\\_religioner/Nepal\\_\(Religion\)](http://denstoredanske.dk/Sprog%2c_religion_og_filosofi/Religion_og_mystik/Indiske_religioner/Nepal_(Religion)). Accessed on 17/9/19.

National Federation of the Disabled - Nepal. (2016). *Introduction to National Human Rights Summit of Persons with Disabilities*: <https://www.nfdn.org.np/news/nhrs-info-eng.html>. Accessed on 17/9/19.

Nickel, J. (2002). *Is Today's International Human Rights System a Global Governance Regime*. *The Journal of Ethics*, Vol. 6 No. 4.

Nielsen, P. S. (2001). *Nepal: En politisk og økonomisk oversigt*. Udenrigsministeriet.

Niezen, R. (2003). *The Origins and Indigenism: Human Rights and the Politics of Identity*. University of California Press.

Nordentoft, H. M. & Olesen, B. R. (2014). *Kommunikation i kontekst*. Munksgaard.

Parent Federation of Persons with Intellectual Disabilities. <http://www.pfpid.org.np/>. Accessed on 17/9/19.

Pillay, N. (2008). *The Corporate Responsibility to Respect: A Human Rights Milestone*. United Nations High Commissioner for Human Rights.

Rienecker, L. & Jørgensen, P. S. (2012). *Den gode opgave - håndbog i opgaveskrivning på videregående uddannelser*. Frederiksberg: Forlaget Samfundslitteratur.

Renteln, A. (1988). *The concept of human rights*. Anthropos, Bd. 83, H. 4./6.

United Nations. *About the UN*: <https://www.un.org/en/about-un/>. Accessed on 17/9/19.

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### 10.1 Interviewguide staff

<b>Briefing</b>	
Anonymity and recording	We would like to inform you that the interview is going to be recorded, but it will be anonymous, which means that your real name will not be used in the assignment.
Purpose of the interview	The purpose of this interview is to understand the life conditions of people with disabilities and what PFPID does to improve these life conditions.
During the interview	During the interview, one of us will be asking the questions and the others will take notes and ask questions if necessary.

<b>Topic</b>	<b>Questions</b>
Background	Will you please introduce yourself with: <ul style="list-style-type: none"> <li>• Name</li> <li>• Age</li> <li>• Job/education</li> <li>• Caste</li> <li>• Place of living</li> </ul>
The attitude towards people with intellectual disabilities	How do you think the life conditions of people with intellectual disabilities are in Nepal?  How do you experience the way people look at persons with intellectual disabilities? <ul style="list-style-type: none"> <li>• Do you think the view of people with intellectual disabilities has changed in recent years?</li> </ul> Do you know anyone who has intellectual disabilities?

	<ul style="list-style-type: none"><li>• If yes, what kind of challenges do they meet?</li></ul> <p>Who do you think help to improve the life conditions of people with intellectual disabilities?</p> <p>Does the government do anything to help people with intellectual disabilities?</p> <ul style="list-style-type: none"><li>• If yes, what do they do?</li><li>• Do you think they could do anything differently?</li></ul> <p>Do you experience any social and cultural issues in Nepal?</p> <ul style="list-style-type: none"><li>• Do you think that these have an impact on people with intellectual disabilities and their conditions?</li></ul>
PFPID	<p>Why do you think it is a good idea to have an organisation as PFPID?</p> <p>What does PFPID do?</p> <p>What does PFPID do to improve the conditions of persons with intellectual disabilities?</p> <p>Do you need to be a parent or a relative of a person with intellectual disabilities to become a member of the organization?</p> <ul style="list-style-type: none"><li>• If yes, why?</li></ul> <p>What does PFPID do to inform people with intellectual disabilities about their rights?</p> <p>What is the purpose of collaborating with organizations in other countries?</p>

	How does PFPID cooperate with the government?
Development for people with intellectual disabilities	<p>Do you think that people with intellectual disabilities want to be included in society?</p> <p>Do you think it will be possible for people with intellectual disabilities to get included in society and have the same rights as other people?</p> <ul style="list-style-type: none"><li>• (Education, work conditions, respect).</li></ul> <p>What do you think is needed for people with intellectual disabilities to be included in society with equal rights?</p> <p>What do you think prevents people with intellectual disabilities from getting equal rights?</p>

<b>Debriefing</b>	
	<p>Is there something important you would like to say?</p> <p>Thank you for your time!</p>

## 10.2 Interviewguide parents

<b>Briefing</b>	
Anonymity and recording	We would like to inform you that the interview is going to be recorded, but it will be anonymous, which means that your real name will not be used in the assignment.
Purpose of the interview	The purpose of this interview is to understand the challenges that you and your child/children experience?

<b>Topic</b>	<b>Questions</b>
Background	<p>Will you please introduce yourself with:</p> <ul style="list-style-type: none"> <li>• Name</li> <li>• Age</li> <li>• Job/education</li> <li>• Caste</li> <li>• Place of living</li> </ul> <p>Will you please introduce your child?</p> <ul style="list-style-type: none"> <li>• Name</li> <li>• Age</li> <li>• Diagnosis/condition</li> </ul>
Challenges for people with intellectual disabilities	<p>What does your child do in the daytime?</p> <ul style="list-style-type: none"> <li>• School, daycare or other activities?</li> </ul> <p>Who takes care of your child?</p>

	<p>What kind of challenges does your child meet in relation to health?</p> <p>What kind of challenges does your child meet in relation to education</p> <p>What kind of challenges does your child meet in relation to social security?</p> <p>Do you have access to facilities and services that helps your child?</p> <ul style="list-style-type: none"> <li>• If yes, which?</li> <li>• What kind of facilities would you like to have?</li> </ul> <p>Do you get any support from the government?</p> <ul style="list-style-type: none"> <li>• If yes, what kind of support?</li> </ul> <p>How do you experience the way people look at your child with intellectual disabilities?</p> <p>What do you think is needed for you and your child to feel included in community?</p> <p>How would you like the future of your child to be?</p>
<p>PFPID</p>	<p>What is your relation to PFPID?</p> <p>Do you get any support from PFPID?</p> <ul style="list-style-type: none"> <li>• If yes, what kind of support?</li> </ul>

<p><b>Debriefing</b></p>	
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	<p>Is there something important you would like to say?</p> <p>Thank you for your time!</p>
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### 10.3 Transcription key

Code	Meaning
I	Interviewer
IP	Interview person (single interview)
IP1/IP2	Interviews with more than one person IP1 = interview person 1 IP2 = interview person 2
...	Long pause
[pause]	Very long pause/silence
<i>Italic</i>	Emphasis of a word
( )	Emotional expressions (e.g. laughs) as well as remarkable body language
“ ”	Indirect speech

- Briefing og debriefing are not written down in the transcription
- Words like “uh”, “yes”, “okay” or similar are not going to be written every time, only when it is import for the understanding of the interview.

#### 10.4 Color coding scheme

Category	Color	Frequency
Culture and traditions	Blue	22
The view of society	Red	40
Life conditions of PWID	Green	109
Relation to government	Yellow	34
PFPID	Pink	27
Caretakers	Grey	41
Development	Brown	29
Inclusion	Purple	14

### 10.5 Interview with Chaha and Alina

I: Will you please introduce yourself with name, age, education and more?

IP 1: My name is ... and i am nineteen years old and i am studying social work on st. George college and i am in my third semester.

IP 2: I am ... and i am nineteen years old and i am also studying bachelor in social work on st. George college.

I: Can you say something about your caste?

IP 1: i am shresha which means that i am nior so i belong to a different ethnic group and community.

IP 2: Bongini means bramin it is a ethnic group of hindu.

IP 1: We are here as interns in PFPID for a year.

I: How do you think the life conditions of people with intellectual disabilities are here in Nepal?

IP 2: To be honest they are quit not good. When you look at it government has made these plans for them but when it is time to take the action it is not be taken.

IP 1: It has not been implemented, not effectively. There are plans and policies but they are not being implemented.

I: How do you experience the way people look at persons with intellectual disabilities?

IP 2: They do not really say anything. For example if there is a person with disabilities in a public bus or in a public area people just look at them, but they do not really say anything. It is like they emphasize with them. People are not rude. In public busses they do not need to pay their fees. They sympathize them.

I: Do you think there has been some kind of change in the way people look at them in recent years?

IP 1: Yes, recently there has been a change because people are getting educated they now know about stuff like that, but in rural places they believe that if your child is intellectually disabled then it is due to a sin in past life. It is like that. But people are changing their perspective.

I: So there has been a positive development in the way people look at them?

IP 1: Yes definitely.

I: Do you know anyone who has an intellectual disability?

IP 2: Hmm...

I: Maybe not personally but...

IP 1: There was one of the board members of PFPID he is a person with intellectual disability. So yes i know one

IP 2: For me i have in the past worked with disabled kids so from that i know types of disabilities and how they act, so i have interacted with them. That is how we know people with disabilities.

I: What kind of challenges do you think they meet?

IP 2: hmm how?

I: Like in daily life? Is it hard for them to get accepted and how about education and stuff like that?

IP 2: About how parents see them they need a nanny 24/7 to look after them. They might get hurt or fall down, so they need a helping hand. So it is challenging for the parents.

IP 1: It is like they are not independent. They are not able to do their own work, so there need to be someone to look after them.

I: Who do you think help to improve the life conditions of people with intellectual disabilities?

IP 1: I think it is the parents themselves that raise them. Because in Nepal the parents treat them very harshly because they feel like it is because of a sin. So from the bottom you need the parents themselves to treat them properly. This organisation (PFPID) are also made by the parents. The parents are taking initiatives in the benefit of their children.

I: You said that they were treating them harshly?

IP 1: Yes in some places because they take the children with intellectual disabilities as a burden so because they need to be given extra care all the time, so they can not focus on other work, so therefore they take them as a burden.

I: You said something about it before but does the government do anything to help people with intellectual disabilities?

IP 1: Government has made some rules and provided different kinds of cards based on their disabilities.

IP 2: And they get a certain amount of money every month.

IP 1: Every month they get something like 2000 rupees.

IP 2: It depends on what condition they are in and their disability. They (government) make cards in different collars. There are four different cards and collars and they are given to different levels of disabilities and they can show it and get discount in public places like vehicles and hospitals.

I: Do you think they could do more?

IP 1: Yes, because they also have the right to study but there is no inclusion. It is not good, because even in public schools there is no facilities for them. I think more rules should be made.

IP 2: It is like government has made it. They have said that they need to have at least one classroom for them, but at the same time it is not being practised, because there are people who need to take care of them, so

therefore it is not being implemented. It is not like they really care, and that is why it is not being implemented.

I: Do you think that people with intellectual disabilities actually can be included in "normal" schools?

IP 1: I think the ones with minor disabilities can be, but the ones with severe disabilities can be difficult. They need daycare.

I: Do you experience any social or cultural issues here in Nepal?

IP 1: Hmm...

I: You mentioned that in the rural areas it is a sin so have a disabled child. So does religion or the caste system have any impact on how people look at persons with intellectual disabilities?

IP 1: Yeah their mindset is about religion and castes

IP 2: People just see them as you need to be with them all the time. Many do not have the luxury of having one to take care of them. Like i said before they sometimes put their child with domestic animals.

IP 1: And they chain them.

IP 2: If there is no one at home to look after them.

IP 1: They think that they can do some other work and earn money if someone else can look after them.

IP 1: because they give them trouble they chain them.

IP 2: In the rural areas they need to go to the fields which are like hard to get because of mountains and hills, so they have a tough way. So they need to have a solution, so that their children will not get hurt while they are away. So that is the only solution that they have, to chain them. It is not like they want to physically hurt them, but that is the only option they have.

I: Do you think it is a tabu like they are embarrassed?

IP 2: Yeah they are embarrassed...

IP 1: Yes, there were one situation where one of the representatives he had a child with intellectual disability and he and his wife left the child. He was one of the members of the parlement. So even they ministers do stuff like that.

I: So do you think that the caste system and religion have an impact on the way people look at people with intellectual disabilities?

IP 2: I do not think for the people with disabilities there is an impact from cultural issues. That is a hole other side. I do not think that cultural things are affecting them.

I: Do you think it is a good idea to have an organisation as PFPID?

IP 1: Yeah sure, because the things that government are not doing they are doing. So i think there should be established more organizations like PFPID, to advocate for their rights.

IP 2: This shows that parents do care for them. It is not like they are doing it for just showing off, they really do care. Parents takes acting for their own children.

IP 1: The parents can help their children like no one else. They know what they need and about their problems, so it is easy for them to advocate.

IP 2: When you have more parents coming together they get in a community. They will share their problems, and find a solution.

I: So you need to be a parent or a relative of a person with intellectual disabilities to become a member of the organization?

IP 1: You need to be a parent to become a member, or at least to become a board member... Or no you need to be a parent to even be a member of the organization. Other people can not become a member.

I: Why do you think you need to be a parent?

IP 1: I do not know that. Maybe because the organisation is a parent federation, because there are many other organisations that are not parents, but they are also not working for them.

I: In what way does PFPID help people with intellectual disabilities?

IP 1: Actually it is an umbrella foundation and it has many networks in different parts of Nepal, so whatever their problems are and if they need something or if there is a new policy PFPID will write a letter and then PFPID will advocate to government.

I: What does PFPID do to inform persons with intellectual disabilities about their rights?

IP 2: They have certain programs where they have facilities and where they train people about people with intellectual disabilities. They have certain books about what you need to do and how you educate and can be a useful source for your child.

IP 1: And how to get a nice future. As i said it is an umbrella organisation and there are many other organizations talking directly to people with intellectual disabilities but PFPID talks with the parents to help both them and their children to know about their rights.

I: What do you think is the purpose of collaborating with organizations in other countries?

IP 2: They can know what kind of situations other countries have, and by collaborating they can learn from each other and help each other. So they can be helpful to each other.

I: How does PFPID collaborate with the government? Do you know that?

IP 2: We do not really know much about that.

IP 1: It is like they write a letter and give to the office first so they ensure that it is a legal process.

I: Do you think that people with intellectual disabilities wants to be included in society?

IP 2: They want to do what everybody else are doing, but there are so many things coming in between them.

IP 1: I feel like when they wants to do something by themselves people are like "you do not need to do it, i will do it for you".

IP 2: Also in Nepal there are not many infrastructures which are disabled friendly. That also create a boundary for them to participate in different things like everybody else.

I: So do you think it will be possible for them to be included in society?

IP 1: It is kind of hard but if you believe in it nothing are impossible.

I: Do you also think it is possible for them to get the same rights as other people?

IP 2: I mean there is a rights to equality, but we need to make sure if they are being meet or not. They have been violated of their rights.

IP 1: I think they will get more rights than normal people if things were actually implemented.

I: What do you think is needed for them to get included in society?

IP 1: I think at first the perspective of people need to change. They need to be welcoming people with intellectual disabilities in society.

IP 2: That is how it starts, because government does all of these things but when people have their mindset they need to change it.

IP 1: Yeah there need to be shift in the way people look at them.

I: What is the perspective right now?

IP 1: It is like people with intellectual disabilities can not take care of themselves, they need someone to look after them. They are not independent and they can not do anything by themselves. But even some of them can do stuff by themselves. Like one of the board members of PFPID she can now go around by herself. I think that is a good thing. So i think we should let them do what they can.

I: What do you think prevents people with intellectual disabilities in getting equal rights?

IP 2: First of all they need to be given chances so that they can show themselves and to participate, and they have not been given, and that is what prevents them to be moving forward.

I: So they need the chance of showing what they can actually do?

IP 2: They have potential, but they can not show their full potential. People are like "you are disabled you can not and you are limited of what you can do". That is how they see them, but with somethings and better opportunities they can do even better than us.

I: What kind of opportunities are you thinking about?

IP 2: First of all we need to give them a platform and give them the training that they need and facilities. There are all these institutions that wants to help them, so in the future they will be independent.

IP 1: We can train them something that they are interested in and if they are interested they will give their best, and therefore the outcomes will also be good. So i think they should be given opportunities to show their talent.

I: You were talking about the board member who has a minor form of intellectual disabilities, but what about the ones who has a more severe condition. Do you think it is possible to give them the same rights?

IP 1: No because the ones with a more severe condition i do not think they are even aware of what they are doing.

IP 2: No because for example a girl who had a severe disability she needed to have a caretaker 24/7 or else she would fall down. Her teeth were missing because she fell down. So in that case it is kind of separated. They need that take of support. But down syndrome and autism they can do stuff by themselves.

I: Do you think it is harder to include people with intellectual disabilities than people with physical disabilities.

IP 1: I think yes. Because people with intellectual disabilities they have different form of severeness. Not everyone can be included, but people who are physically disabled they can do more by themselves.

IP 2: It also takes alot for the people who are taking care of them. They need to understand that it is not even possible for them to survive without help.

IP 1: I think even the caretakers should be given training, so that they can motivate them. They are with them 24/7 so they play an important role.

IP 2: And even the caretakers can teach them stuff. For example i taught them how to cross the road, and that comes from the training. You need to continue the training so that they can remember, it is not like with us who learn it once and then we need to remember it all.

I: What kind of facilities does the government provide to families with intellectual disabled children?

IP 1: I do not know about the families but in certain hospitals there is separate work for them. And even banks give them seperate counters. For the families i do not think they are given much.

IP 2: They are given some amount of money and i think there was a policy where they get a caretaker for their child, but i am not quite sure. I think that is really useful.

I: So every family does not get a caretaker?

IP 2: No.

I: So what if they do not get a caretaker what do they do?

IP 1: Either their grandparents will also be at home and live with them or if the mother is a housewife they will be with her. I do not think they hire a caretaker only if they belong to a high caste family.

IP 2: You need to be able to afford it.

IP 1: You do not get one for free by the government. It is not easy to get a caretaker. Even the caretakers do not want to work with the intellectual disabled children.

IP 2: They can not even look the other way for a short time because if something happens they might get the blame.

I: So the caretakers thinks that it is harder to take care of intellectual disabled than others?

IP 2: Yes, but there are some taking care of them except from their parents. Parents have jobs from nine to six so caretakers are there to look after them.

IP 1: Some parents keep their children in daycare so that it is easier for them to work.

IP 2: But it depends, you need to be able to afford it. Because where i volunteered last year it was only doctors, lawyers and businessmen, people that can afford it.

I: is it possible to have your child in a daycare center for free?

IP 1: No you need to pay some amount of money, but there are other institutions for middle class families.

IP 2: They also sponsor some of the kinds from the rural areas, but otherwise you have to pay.

I: So it is not possible for every family to get their child in daycare?

IP 1: No...

I: Are there a lot of daycare centers or is it mostly in the bigger cities?

IP: No mostly in the cities.

I: Okay, so it is hard for people in the rural areas.

IP 1: In some places people feel ashamed to say that they have an intellectual disabled child so they hide their child in their home.

I: Why do you think they are feeling ashamed?

IP 1: It is like people wants to have a normal child without disabilities and when you have a intellectual disabled child people think it is because of a sin.

IP 2: Other people also think that "oh your child is not going to have a normal life and will not succeed in life, he is not gonna get married and have a job".

I: So people value a "normal" life here very high?

IP 1: They want someone to take care of them when they grow old, but actually they have a child who is intellectual disabled they should be taking care of them instead.

IP 2: It is not like parents are not doing anything. I have an uncle who is in some way disabled and they make sure to make him independent from a really small age, so that i can do stuff on his own, so that we do not have to be there 24/7, but of course they are scared about he is doing. He can at least do some stuff on his own he has like a normal small job in a shop, where he is helping.

IP 1: I think more parents should do like that.

IP 2: Also my mom's friend she had epilepsy and her family thought if they married her off she would learn some work and it will get better, but she was getting a lot of violence in that family. It is another mindset that parents tries to just marry them off, because they believe things will get better.

I: Is it easy for them to get married off?

IP 2: as in the case we still have arranged marriage, so they find families and the do tell about their child's disabilities and are you willingly to accept it? But i have seen cases where it did not worked out. Even with my own uncle it did not worked out.

IP 1: Most of the times i have not seen them getting married

IP 2: As i said before i have seen to cases with my uncle and my mother's friend who where married off, but in both cases it did not went well.

I: So they got divorced or?

IP 1: Yes, i think it is quite hard with people with intellectual disabilities. In some cases i think it is easier for physically disabled to get married off. I think it is more common that they gather and introduce themselves and them get married.

I: Okay, we do not have more questions. Do you have something that you would to say?

IP 1: I think it is common that people with intellectual disabilities get married in other countries but not in Nepal. But maybe if both of them have a minor disability they can be married. I just remembered that there is one ex-member of the organisation who are intellectual disabled, he visited PFPID, and he is married and both of his children are normal. His wife also has something, but their children are good. One is eight and one is three. We asked him if they were doing good and he said that the girl was one of the best in her class and stuff like that.

## 10.6 Interview with Binsa

I: If you could start introducing yourself?

IP: Okay, I am ..., working in PFPID since one and a half year. I joined PFPID in 2018 May most probably. PFPID itself is a parent federation of persons with intellectual disabilities. It established in 2011 and it is working on the field of advocacy for the need and support of persons with intellectual disabilities. It is the umbrella federation of the parent organization, which do the advocacy work in policy in local government level for the oral development in the field of persons with intellectual disabilities. Are you getting my point or my English is so much bad to you to understand?

I: We understand. What is your education?

IP: I have completed my masters in economics and also the bachelor in law.

I: And your age?

IP: I am twenty-eight years old.

I: Okay, what caste are you from?

IP: I am from Brahmin family. But I would like to say that I myself is a person with disabilities. I am of low vision. I think you have not known before?

I: No, not at all. How do you think the life conditions of people with intellectual disabilities are here in Nepal?

IP: How much time have you spent here in Nepal?

I: Three weeks.

IP: Basically more or less you have also some certain idea about it. The living standard of the persons with intellectual disability and their parent is not so good. Most of the parents are in the line of poverty i guess, so they have to face the hand and mouth problem as well. It is the condition of the persons with intellectual disability. In average.

I: How do you experience the way people look at persons with intellectual disabilities?

IP: The society is now accepting because of the advocacy and the policy development, but before the society had not looked them in a most positive way. They felt that the persons with intellectual disabilities is the

curse. Because of the curse they have the problem, so they used to humiliate them. They do not want to socialize them.

I: So it is getting better now?

IP: Yeah, it is getting better now because of the legal provision also and because of the frequent advocacy also it is getting better. Not *as* much better than we expected.

I: Okay, so you still think that it can get better?

IP: Yeah.

I: Do you know anyone besides yourself who has some disabilities?

IP: Yeah our (name) who is also working as a finance officer, she also has a problem of low vision.

I: What kind of challenges do people with intellectual disabilities meet in daily life?

IP: The scenario is that persons with intellectual disabilities cannot understand the word the society is doing for them. They cannot understand what violence are they facing through. Now many resource classes and daycare centers is here for the persons with intellectual disabilities. But the situation is not so good.

I: Why is it not so good?

IP: It is in the progress condition. Now it is changing. It takes a long time.

I: Who do you think help to improve the life conditions of people with intellectual disabilities?

IP: The most important thing is the legal provision and the policy development. If we have legal provision and if we can address their problems in the policy, then definitely the government will take some specific steps for them. And the second is that we have to improve the living conditions of the parents of persons with intellectual disability, because if the parents can earn their living, if they can earn their livelihood, then only they can provide good educations and good living standard with their children. So mostly we have to focus on the economic generation activity of their parents i think. The next thing is to provide the proactive training to the learning disabilities for persons also. Because if we provide them with proactive training, and if we try to analyze their intellectual capacity, and if you try to analyze their skills, then we can provide them with proactive training as for their skills, so they can earn their living can be good also.

I: Does the government do anything to help people with intellectual disabilities right now?

IP: We have different policies, the card distribution policy, the disability policy and many more other policies. We are doing our best. Our organization is doing the advocacy. The looking attitude of the government is also changing.

I: Do you think that the government could do anything different?

IP: ... Anything different? What can it do? It can provide the information through making manuals and it can do better by addressing the problems and in legal provision also.

I: Do you experience any social or cultural issues in Nepal?

IP: I am not getting you please.

I: Do you think that your culture or the structure of the society has an impact on people with intellectual disabilities? Do you think that they

IP: Yeah they look like a pity. They feel pity with the persons with disabilities. Because in their perception they think that the persons with disabilities could not work by themselves instead of providing the environment. They used to show the pity and they cannot do the work themselves, so we have to support them first i think.

I: Why do you think it is a good idea to have an organization as PFPID?

IP: Because of our organization and because of our advocacy we are able to address some provisions in the policy development as well as in the government level also. Because of this organization many more persons with similar interests and problems gathers together and collectively they can raise their issues. Collectively issues can be addressed in the future.

I: What else than advocating does PFPID do? What kind of work besides that?

IP: The prior work of PFPID is advocacy. Besides this we have our member organizations, 38 member organizations in 35 districts i guess. Most of the member organizations conduct the daycare centers for the persons with intellectual disabilities. As you can take the example of Nuwakot, we have our daycare center there. Not only there but in many other districts have daycare centers. Our member organizations do advocacy there to the local government for the funding and for the issues of persons with intellectual disabilities.

I: Do you know how many daycare centers you have?

IP: Not exactly. I have to ask (name) for that (laughing).

I: Okay, what does PFPID do to improve the conditions of persons with intellectual disabilities?

IP: The PFPID through our member organizations we provide them the trainings and the advocacy skills. The PFPID itself does advocacy to the central government and we have our parent in the policy making committee. It is mandatory to have the parent of persons with intellectual disabilities making the policies there. It is through our advocacy from the PFPID itself.

I: do you need to be a parent to become a member of the organization?

IP: Yeah.

I: Why is that?

IP: ... (Laughing). I will try to give my best answer. I think because parents no other can understand the issues of the persons with intellectual disabilities rather than their parents indeed I guess.

I: What does PFPID do to inform people with intellectual disabilities about their rights?

IP: PFPID has some easy to learn material, I think you have seen it. Through our easy to read materials and trainings conducted in different places in different member organizations and through advocacy. These are the works that PFPID do.

I: What is the purpose of collaborating with organizations in other countries?

IP: I have no idea about it, sorry.

I: It is okay. How does PFPID cooperate with the government?

IP: Through our policy development the government will provide some fund to us for doing the various kinds of activities.

I: Do you think that people with intellectual disabilities want to be included in society?

IP: Yeah definitely, they are also the human being. They have to get all the rights represented.

I: Do you think it is possible for all people with intellectual disabilities to get included in society and get the same rights as other people?

IP: Yes we have to be optimistic and gradually the environment is changing. I have seen it in my work experience more than one year I have seen. Gradually the perception of persons with intellectual disabilities is changing. I have one example in (name of a city). We have our helper who himself is a person with intellectual disabilities working in our daycare center and earning his living.

I: What do you think is needed for people with intellectual disabilities to be included in society?

IP: What things, sorry?

I: What do you think it takes for people to be included?

IP: First there is the narrow concept of the society that they think that the persons with intellectual disabilities is a curse. They have to change them first.

I: Okay, so you have to change the...

IP: The misconception of society. Then we have to change the education is the prime factor to change the society and to change a person itself.

I: So the society has to be educated on people with intellectual disabilities?

IP: Also from the education and the enlightenment then the misconception of society will gradually decrease. Then we can include persons with intellectual disabilities.

I: What do you think prevents people with intellectual disabilities from getting equal rights right now? What is standing in the way?

IP: Sorry?

I: Is there anything that makes it difficult to get the same rights? Is there something that is blocking for it?

IP: The persons with intellectual disabilities are facing a lot of problems since many years ago. We cannot expect that suddenly the society will change and provide them with all sort of rights and all sort of freedom resented. It is a gradually changing process. Now many positive changes is going in the society. It takes some more years.

I: What kind of problems did they face earlier?

IP: They are not recognized by the society, even the family itself. Now the family of persons with intellectual disabilities are being more educated, so they are accepting their children. Previously that was the situation. The family also feel that it is a curse or something else. Now it is changing gradually. They are advocating for their rights and the rights of their children. The society is a little bit positive towards them. It is a great changes. Before coming in the organization I even did not have idea about on the persons with intellectual disabilities to be frank. This organization saves many children with intellectual disabilities. I come to know about some issues of persons with intellectual disabilities. It is the situation.

I: Do you think that earlier parents felt embarrassed if they got a child with intellectual disabilities?

IP: We cannot say embarrassed. They think that it is because of their luck, their bad luck, that they have children with intellectual disabilities. Now the thinking is gradually changing.

### 10.7 Interview with Dhonu

I: Will you start introducing your name, age and what you do here?

IP: So my name is ..., age 27 and I work as program officer here at PFPID.

I: Ja, what about your education?

IP: So, I am waiting for my final semester results for masters in conflict, peace and development studies, so I have my bachelor in social work.

I: Okay, which caste are you from?

IP: Chhetri.

I: Okay... what do you think the life conditions of people with intellectual disabilities are in Nepal?

IP: So, in Nepal it is basically people with intellectual disabilities are the poorest of the poor, so when I say that.. it is like.. most of the parents are living in the rural areas and most important these days there is a poverty circle, so first of all they are poor and unlike other countries in Nepal we do not have a system of support person or caregiver, so that one of the parents have to be always engaging to care of their children so it effects there their opportunity to participate in economic activities, so that makes them even poorer. So they are poorer and they do not have proper access to help facilities. It is also because of the lack of education that they have and then I also want to link it with stigma, that they do not want to show them to us they keep them lock in their houses... and if one of the parents are only there, is a single parent and they have sometimes chained in their homes, so that the parent can go out for economic activity, so another important thing is that they are subjected to sexual violence as well there are many cases like there is one in Kathmandu where a girl with intellectual disabilities was raped several times... the bus driver and his support-person with the bus they continuously raped the girl and she was not able to... complaint it anywhere because she cannot... so this things are quite... average in the case of Nepalese scenario and they also do not receive proper social security fx... we have three no four different kind of cards and for red card they receive 3000 per month and for blue cards it goes on decreasing, so the yellow and the white are the... mild and the last form of disabilities, I can not say now, I forgot it, so yeah, so the two types of disabilities do not receive any

kind of support from the government, so the 3000 that they receive is used by their parent for other purposes that they do take proper care of their child, so that is the thing they also lack of education... the mainstream school are not willing to take them, because they think that their involvement in the classroom activities will disturb other students and other students maybe not show up in the schools and even if some pupils are there in the schools they also fear discrimination and exclusion and bullying from other children, so that is the general conditions of children with intellectual disabilities to add more... until now I have not seen any persons with intellectual disabilities that has been engaged in any form of employment or economy so so that is also lacking, it is also because no education no proper skills and with the former disabilities they are... the job provider are also not trying to take them so that is the general condition of people with intellectual disabilities also according to the last sensors the total population of intellectual disabilities in Nepal is 4888 which are disabilities organisations including PFPID claims to be incorrect and the evidence for that is that the minister of education produces of last report so end of last report it is concluded that the inclusion of children with intellectual disabilities in schools is more than the total population that the sensors shows it is also because the people that were involved in taking the sensors were not trained and also of previously before the sensors from the urban areas of PFPID and other DPO few district sensors collectors were provided with some small form of trainings and those who received.. those people that received training and they went for other sensors those districts... so that there are larger number of people with intellectual disabilities so and the next thing is that if I am sensors taker and I go to a house to take a sensor their parents will not tell that they have a person with intellectual disabilities, so they hide, so we do not know that actually population, so that is a central thing about... intellectual disabilities.

I: You mentioned stigma and discrimination but how do you experience that people look at people with intellectual disabilities... like their attitude?

IP: The stigma is based on the fact that it is the result of the parents worst things in previously life or something like that, they do not like it to medical reasons or other things like that so it maybe there be some bad activities in previous life or they had done some bad karma in their previously life so that is the reason why they are getting this children, so that is one thing and then... the parents also do not take the children to the festivals in public spaces and other things, so that maybe disturb in those places or they maybe run away like that and the persons with having and organising some kind of festivals also do not want the parents to bring to those kind of cultural events so this is the racist things that end up with stigma.

I: So you think that they are ashamed or...?

IP: Someone yes, and also they want them to remain in the homes.

I: Okay, do you think it has changed? Has there been any development on this... how they view people with intellectual disabilities?

IP: So, it depends on the level of education within the parents and the location that they live in. In the urban areas this has significant changed, the parents are taking to different kind of public spaces and cultural events and different or other places but in the rural areas this is almost the same.

I: Okay, do you know anyone who has an intellectual disability.

IP: Definitely...

I: A lot?

IP: A lot, yea...

I: Also in your family or from your work here?

IP: Only from the work, I do not have anyone with intellectual disabilities within my family.

I: What kind of challenges do you think people with intellectual disabilities meet... that you know?

IP: So already then I mentioned on the health education, social security and all that livelihood and in activities and in these aspect they face a lot of challenges and it is also that the sexual reproductive part of intellectual disabilities are not considered... I have two or three examples of the intellectual disabilities getting married other than that they are not married there are many people with intellectual disabilities over 30 years of age 40 years of age who do not have a sexual life which is considered to be something within themselves and that it is not our society that also not is that expressive when it comes to sexual, reproductive rights and health, so that is also one reason and the next is that people are also not willing to marry them there are also cases where the females have the menstruation problem right so they... what they do are that they remove the

uterus so that they do not spread any kind of... this cases are not reported much but then we know it because we have been working in this field.

I: Okay, who do you think are helping to improve people with intellectual disabilities' life conditions?

IP:... It maybe government, the government to some extent but I would say mostly the non-government sector has done a lot.

I: Do you know what the government does to help people with intellectual disabilities?

IP: So... they provide some kind of social security... like they provide 3000 nepalese rupees in theory they also provide different cards, types of cards so from that they can get transportation, easier access to health services having said so that is not translated to when it is implemented, so the government makes some kind of rules but then the ones who are there to implement those rules... like look after the rules busdriver and the one who is suppose to take the money while we are travelling do not know all the different types of cards... so, when someone shows a cards, what is this, so they do not know.

I: So the rules do not really work?

IP: Yes, so there is also different policies like disabilities seats in the buss as well and then the government also provides including education policies which said that the children with intellectual disabilities are also... should also get education in the mainstream schools and not get admission to the intellectual disabilities as punishable act as well, so this kind of law as they are nepalese member of the CRPD and all that they have signed and vertified in different types of... policies that provides rights to the persons with intellectual disabilities there are many rights but we lack in implementation, proper implementation.

I: What do you think the government could do differently?

IP: So, what I think is that at this point of time the major focus of the parents are that their children are engaged in some kind of economic activities, so I think an economic center where their parents can get some kind of skills and also provision of support person for the person with intellectual disabilities so that their parents can go and work for the economy of the family, so I think this kind of activities would be more helpful and regular support in different aspects of the families life should be provided by the government also to add

to that I think the government should also have some kind of entertainment activities, when I say entertainment activities is a place where the children with intellectual disabilities can socialize with other normal children, so that they do not remain isolated and other people also change their perception towards intellectual disabilities and learn from each other.

I: Do you experience any social or cultural issues in Nepal... you mentioned something about the traditions... like some obstacles that makes it difficult to improve people with intellectual disabilities' life conditions.

IP: I did not get the actual question.

I: You said something about sometimes people believe that... if they get a child with intellectual disabilities it is because of a sin committed in previous life, so do you think religion and the caste system has any impact on the life conditions of people with intellectual disabilities?

IP: Yes, so I do not actually know if something like that is written in some religious text or something like that but it is general people meet and believe, so I do not know who told that, that the previous sins... brings children with intellectual disabilities to the family but they feel and they want to believe that, yes this maybe be the reason as well also they also will not know the actual reason of why they have children with intellectual disabilities, so that is also the reason that when they do not have something concrete to believe on so they blame the previous sins and the act of god.

I: So, it is maybe a lack of information?

IP: Yes.

I: Okay, why do you think it is a good idea to have an organisation as PFPID?

IP: So, the government have been trying, I do not say that the government does nothing, they have been trying but it is important to have like PFPID, it is a organisation of parents so they can speak for their children so the children cannot speak for themselves... so it is the need that the parents feel for their children that they work for and as I already mentioned that the parents lack a lot of preparation and face a lot of economic problems, so I think to work with them and to improve their skills for other kind of activities and all that to make sure that the government actually does what they the policies say so keeping press for the government

and also to have base practices around the globe and to relate it to nepalese context and then implement as good practices which is good for the civil society and the organisation like PFPID to work for intellectual disabilities.

I: You already explained it a bit but can you describe what PFPID do?

IP: So PFPID is basically the organisation of the parents, so it is a federation organisation to out Nepal, so the main focus of PFPID is lobby and advocacy for the rights of people with intellectual disabilities and also... it also helps to provide education about intellectual disabilities to the stakeholders... the research on intellectual disabilities and passed to the general public and also to support the government on different base practices from the world around so that the government can translated it into the programs also providing some kind of activities for the parents and their children so this kind of activities are basically done by PFPID, so it is mostly softer kind of things not harder kind of things, that PFPID does.

I: Do you have to be a parent or a relative to be a part of PFPID?

IP: Yes, it has to be the immediate parents, so if the immediate parents are not there... so it has to be someone who has been taking care of the child and it has to be certified by the local government and only they can be a member of PFPID.

I: Why do you think it is so?

IP: So, in some cases the parents... have already died and they are not taking care of and the persons who are close to those persons are taking... benefit of want should have been addressed to those persons and also measure policis so we attend to work with other of parents more.

I: What does PFPID do to inform people with intellectual disabilities about their right.

IP: So, under PFPID direct supervision and direct... management there are information of people with intellectual disabilities it is called associating of people with intellectual disabilities in Nepal so it provides training to them about the laws and regulation and also how to advocate for themselves it also provides international exposure for people with intellectual disabilities like the word congress of inclusion where they go to participate it is also important that the children meet each other in different types of training... so that they can

have pair support with each other and also not remain isolated so it is not only that training provides information it also means that the people with intellectual disabilities meet each other and then talk about what they want it is not only about empowering and building the capacities indirectly the second aspect is that they meet with each other so when people with intellectual disabilities comes their parents also come as a support person, their parents also can meet with each other and share how they feel and how their sorrows and learns from each other, so I think it is mostly trainings and workshops that PFPID does to let people with intellectual disabilities know about their rights.

I: Okay, what do you think the purpose with collaborating with other organisations in other countries are?

IP: So, it also builds the capacity of PFPID and to learn base practices from different countries and also international solidarity so it is not only a country thing to look after... and children with intellectual disabilities but it is a global thing, so I think it brings international solidarity, learning from each other and builds networking and also we can have collective press... to improve the life of people with intellectual disabilities.

I: Okay, how PFPID does cooperate with the government?

IP: When you say how?

I: Yes, how do you work with the government? What kind of connection do you have to the government?

IP: So, I think we have a good relation to the government, they are invited to different programs of PFPID, PFPID are also called for different programs and also while drafting different policies we have a consulting meeting where PFPID also is invited so we share our part, we share our issues that needs to be addressed by those kind of policies, we provide feedback to the government and sometimes the government also funds PFPID to implement some kind of activities for people with intellectual disabilities.

I: So, you have a good relation?

IP: Yes.

I: Do you think that people with intellectual disabilities want to be included in society?

IP: Yes, definitely!

I: And do you think it will be possible for people with intellectual disabilities to get included in society and have the same rights as other people?

IP: As for my perspective my personal opinion, I think that it is... I think that people with personal want to but... it is very difficult it takes a long period of time so it is the cultural thing and a social thing that has been for ages, so it takes time to change, mindset do not change in a click, right? So it takes time but eventually it will happen, so we are positive on that. (Red + Purple + Brown)

I: What do you think is needed for people with intellectual disabilities to be included in society with equal rights?

IP: So, the most important aspect is that governess, education level and providing information of intellectual disabilities the correct knowledge the scientific knowledge and to the parents but not only to the parents but to members of society so that they can live a dignified life. (Purple + Brown)

I: Okay, you already mentioned it but in tradition and the way they look at them but do you think that there are anything else that prevents people with intellectual disabilities from getting equal rights?

IP: It is mostly cultural things.

I: So do you think that the cultural mindset has to change for them to get included?

IP: It is not always cultural things fx... intellectual disabilities also comes with other forms of disabilities like physical disabilities, so the geographical here in Nepal it is not that easy to move here and there, so I think that geographical thing also and economic, so it is all combined.

I: So, you have to improve all these part?

IP: Yes.

I: Do you know how many daycare centers you have?

IP: 253 somewhere around that... so it is between 200 and 300 for intellectual disabilities so in Nepal we have provision of resource class, resource class is class for only children with intellectual disabilities... only children learning in the centers and there are 2-3 special schools for intellectual disabilities and the rest of them are resource classes... the resource classes are something like, the children come... and then they never upgrades, so it is the same class every year they go... they do not learn much of things only they are playing with some kind of instrument and all that.

I: So they do not really develop?

IP: No, do not really develop.

I: Are the daycare centers normally placed in the bigger cities or do you also have daycare centers in the more rural areas?

IP: So, the daycare centers and the resource class are different. So, the resource class of the government are also located in different part of the country in rural areas as well but they have a lower capacity, they can only take 10 or 20 based on the resources that they have or there are more children within the district that cannot fit in the resource classes.

I: You told us before that you need to be a parent to become a member but can you be staff here without being a member?

IP: Yes, staff is different and member is different.

## 10.8 Interview with Faneel

I: Will you please introduce yourself with name, age and so on?

IP: My name is ... I am president of Parent federation of persons with intellectual disabilities here in Nepal. I am a parent of intellectual disabilities. My son he is 21 years old, he is severe intellectual disabled. Bathing, eating and more is not possible by self. We have support from his mother, family and sometime also me. Especially I am working for PFPID and now days i am working for the rights of people with intellectual disabilities, as employment, education. We are fighting for raising awareness of persons with intellectual disabilities. In PFPID the working areas are consulting, advocacy and training. It is an umbrella organisation of persons with intellectual disabilities in Nepal. The members are parents and also sometimes we have capacity of government and stakeholders, so we are raising awareness. We have also collaboration with our member organisations and stakeholders, and we have networking. Another part is advocacy, that is the most important thing and the main focus. We are advocating for the new constitution, acts and legislation. We are making new guidelines and budget and policy, and sometimes we also work for implementation of the same things.

I: How do you think the life conditions of people with intellectual disabilities are here in Nepal?

IP: They are a marginalized group, as other ethnic groups, there are so many. It is a poor living condition. The ones with disabilities are more marginalized in here in Nepal. Intellectual disabilities are more marginalized, as psychosocial disabilities, down syndrome and more, because they have not education and they have not enrollment in school management community. They have not agreed and they do not have enrollment for school legislation. They have many challenges, sometimes also discrimination also by family, sometimes also with parents and also neighbors. The discrimination and marginalization is not specific in the policies, programs and services in local government.

I: How do you experience the way people look at persons with intellectual disabilities?

IP: So many persons in society look down on physical handicap, but not so much with intellectual disabilities. Most people know about disabilities so I think it is okay. The question is what kind of disabilities?

I: What kind of challenges do you think people with intellectual disabilities meet in daily life?

IP: They have so many barriers in their life. They have many modern problems. The ones with physical disabilities they can say I want bath, food, dancing, go out and others, but people with intellectual disabilities they cannot. Everytime they are just sitting in their home, and that is so difficult. In the last ten years there has been a change in society, but still so many, and also parents, are not accepted in society. They cannot go to school, get married. The society has not accepted. Sometimes they do not have support from the parents and society. It is difficult.

I: You said that it has changed the past ten years?

IP: Yeah a little change ten years back. Now a days they can go around by themselves without neighbors and society is looking at them. Roads are also better now. So it is not the same situation. Government are also doing policies, so we are raising awareness. Government are now asking: "okay what is the problem, we will support you and manage everything". They are a little bit interested for the support. So they want to support and to increase the policy and budget. So a little bit change from ten years back.

I: Who do you think helps to improve the life conditions of people with intellectual disabilities?

IP: Government and stakeholders are now listening to our issues, so a little more service from the government side, like education and health service, but this not for people living in remote areas. For them there is a lack of awareness and knowledge. They are not getting service from government and social security.

I: So are there better services and facilities in the bigger cities?

IP: Also not for every person in bigger cities. They get ID card but not for every person. Current situation not more than 60 percent, maybe around 50-60 percent with intellectual disabilities have ID card. Around 40-45 percent have not ID card.

I: Do you think that the government should do anything different?

IP: They are aware of the card. After the federal system everything have changed. Not every local government is so good example. They have data, services and facilities and that is good, but not all of them have. But the ID card is in 750 districts.

I: Do you think that religion or the caste system have an impact on the life conditions of people with intellectual disabilities?

IP: Yes, there has been a change in some castes as Brahmin and chhetri, but in some not. There is more marginalization in some castes. There some very poor communities, but government want equity for changing the society.

I: So it is different to change the mindset of society?

IP: Yes. Also in maybe first class there will be ten boys and ten girls and then in seventh class there will still be ten boys but only five, but that has also changed now. There is more equality. Around 20 or 30 percent drop out of school and especially girls. Also during menstruation time girls do not have good sanity, but now we have so. so now a days the mindset of society has changed. And also we have discrimination from parents in home, but that is still mostly in the remote areas.

I: Why do you think it is a good idea to have an organisation like PFPID?

IP: PFPID is good for changing the culture, because in some casts it is not good. We will remove the bad culture from society. In PFPID we also manage workshops especially for the mothers. We train in why to care and how to care. In the future we will also do special training for the father about how to manage.

I: You mentioned training and advocading. Do you do other stuff than that?

IP: We also do counseling.

I: So what does PFPID do to inform people with intellectual disabilities about their rights?

IP: We have advocating for this and for every legislation like the CRPD. CRPD is a very strong instrument for disabilities. It is not only for Nepal but for global. We are fighting for the implementation of the CRPD and legal framework in line with CRPD.

I: What is the purpose of collaborating with organisations in other countries?

IP: The CRPD mentions in article 32 the support of collaborating with any non-developed country. It is not only for the financial support. We want the technical support and knowledge sharing. It is a partnership, and we want partnerships to ensure the rights of people with intellectual disabilities.

I: Does PFPID cooperate with the government here in Nepal?

IP: Yeah! we have good collaboration with ministers especially with the department of education and health. It is a good relationship. We have partnership and every year they support us (PFPID) with a little budget for programs.

I: Do you think that people with intellectual disabilities would like to be included in society?

IP: Yes. All the working about advocating, raising awareness, capacity building all that is for the inclusion in society. All mentally disabled should be included in society. Every strategy is for the inclusion of intellectual disabilities. In their family, in school and in society.

I: So do you think that it is possible for them to be included in society?

IP: Yes.

I: So what do you think is needed to be done for them to be included?

IP: In ten years we have been working in this area but we do not support and cover every area in the country. We cover four district areas. There for many parents do not know about the PFPID. I think every parent should have support for their child. For the parents it is important what will happen to them in new life, so they are worried about this issue.

I: What do you think prevents people with intellectual disabilities from getting the same rights?

IP: The human rights is the same for every person, but humanity is diversity. There is different diversities for every person. Every person they have need and some special needs. Not the same needs for every persons. I think for persons with intellectual disabilities they are not accepted for their special needs. Maybe people with intellectual disabilities have five needs. Not the same needs.

I: So do you think that society should consider their special needs?

IP: Yeah yeah. Society, government, parents and stakeholders they know about the intellectual disabilities after the change of society, but some have lack of knowledge and about disabilities and how to support them, and how can they support us also.

I: That was the last question. Is there anything else that you would like to say?

IP: Okay... I think you mentioned the thesis of persons with intellectual disabilities and the Nepali culture and society, so thank you for that and the nice topics. It is good to raise awareness of the issue and this area. So thank you for choosing this topic.

I: You are welcome, and thank you very much for your time!

## 10.9 Interview with Amita

I: Will you please introduce yourself with name, age, caste and so on?

IP: So, her name is ... and she is 52 years old and she lives in ... in district five and she don't have job and no education at all.

I: Will you please introduce your child?

IP: Her name is ... and she is 15 years old. She studied until class two, she was going to school but that was not so nice. So, what she is saying is that when she was one-and-a-half-year-old some people did the magic, the black magic to her child. So, in one month she was sick in a bed unconscious, so they took her to the magician to do the rituals. They worshipped all the Gods and in one month she was in the magician home and then she was worshipped. She has also been gone to the doctor and they checked all the things, but they said it is because of pneumonia a cold in the chest, so because of that she is like this, their thought is that it is because of the black magic. She was born very lucky, so people threw the black magic.

I: Why was she born very lucky?

IP: It is a saying that she was born very lucky, so because of jealousy she got the black magic and then it happened (her diagnose).

I: What does your child do in the daytime?

IP: In the daytime she doesn't go to school, but they have planned to get her into day-care centre, but now she just plays and wash clothes, and talk with her sisters and mother. That's how she spends her daytime.

I: Okay so she doesn't normally stay at the day-care centre?

IP: No, but they have planned to.

I: Who takes care of your child?

IP: Normally she does, her mother and also her other sisters and relatives, but normally she usually takes care (the mother).

I: What kind of challenges does your child meet in relation to health?

IP: So, what she is saying is that when she was sick in one month that time is the biggest sick that she got. Since then, since on month she went to the magician did all the worship rituals. The magician told her that they should come and do it every year in six years. So, they have been going to the magician every year and per year they have to pay 15000 (NRP). So, they have been doing the worship, but now they finished because now she is 15. So, she has not been suffering from big diseases, but normal fever sometimes and common cold, but after the worship rituals she has not been suffering from big diseases.

I: Who is doing the worshipping?

IP: There is a magician in Patan, and she is omen so she is doing that.

I: Is it easy to get 15000 every year?

IP: They are saying that it is very difficult for them to do that, but their daughter she has to do. After six years the magician said that she was okay, so every year in six years they had to pay 15.000.

I: Is her husband working or how did they get the money?

IP: Her husband works in government office, so per month he earns 20.000, but they have five daughters and one is she and then four others. They are all educated, and one has already been married.

I: What kind of challenges does your child meet in relation to education?

IP: She was sent to the school and then she did not know how to write and read so they the teacher said that "you better send her to the disabled school; it will be nice, and it will improve her". But what they think is that it will be the same in that school, so they think she should better stay in the home. Her sister also tried to teach her the words and terms, but she doesn't recognise the words, so she should rather collect paper

and pen and wright in her own ideas and terms. So, the parents thought that it was better not to send her to the school. So, she is not learning in school, but teachers told them to send her to disable school.

I: So, they have a school in this area for people with disabilities?

IP: Yes, this one (the day-care centre)

I: Do you have access to facilities and services that helps your child?

IP: The facilities that she is getting is from the government. The government has divided into a card system, so she is getting the red card and that is 3000 per month, but now again the investigation has come and now they are saying that they will not get red card because now she is talking and doing the stuff, like washing, so they are not giving, but it is not final, but they are saying that.

I: So, they are not sure if she should get any?

IP: Yes, because blue gets 600 per month and red 3000 and white will not get anything. So, after checking they will give card according to that. Earlier she was getting red card 3000 per month, but now they are again checking, and they have not decided which card to give to her.

I: Is it because she is in a better condition?

IP: Yes, because she is now talking and stuff.

I: Does she get any other help than from the card except from the 3000?

IP: The card will also get her free into hospital if she gets sick, so she will get free cost help in hospital. And in the bus also they will not take cost. But she is not being so sick so the card is not being used, but they will get service form the card.

I: What kind of facilities would you like to have?

IP: She wants her child to be in a school. Not like this in one room, but in a good school with same kind of children, but with good facilities. That kind of service she wishes to have.

I: How do you experience the way people look at your child?

IP: She has not experienced anything. When she is there everybody treat her nice, but she doesn't know what others do if she is not there, so she is a little worried that other children goes to school and she is not qualified to go to school, but when she is with her nobody treats her bad.

I: So, what do you think is needed for your child to feel included in community?

IP: She wants a school for her, but she is saying that one person cannot build a school. The place of this area is also not so safe for the girls because this is a quit area and down there some incident happened already to the normal people also. So, she is scared because her girl has already period, so if any incident happens. This is only one room, and this is a quit place and there are no man only teachers are women. So, she is wondering who will be responsible for her if anything happens. Therefore, she is not taking her child there (day-care centre), because she doesn't feel safe here. She wants a place where everyone can be safe and learn, but she cannot build her own. They will need fond from other side. She also got the opportunity to send her child to another city in a centre, and she would get 10.000 NRP on behalf of giving her child there. They have a hostel so she had to sit there and in one month she will get 10.000 in return. So, they go and checked the place, but there where men, physically disabled men, so they don't send her there.

I: What kind of incident has happened here?

IP: She told that at 10 AM in the morning one girl was going to the office so there were boys who used weed so they tried to rape, so that is why she is feeling insecure.

I: Was it on the way here (to the day-care centre)?

IP: There is a cave here and one teacher was going on that road and got hit and they took away the gold chain and he is now in hospital. That is why she is insecure.

I: Is she insecure about leaving her child here in the day-care centre?

IP: Yes, because these kinds of incidents are happening nearby, and this is also quit place.

I: How would you like the future of your child to be?

IP: She thinks that her future should be bright, but she is a little insecure when she is alive, she will take care of here but after her, her sisters will not take care as she cares. So, she is also a little worried about the future. She wishes her child to be in a safe place and a bright future.

I: She is saying that her sisters will not take care as she does. Why is that?

IP: Because they have to get married and go to other home. So, it will be difficult for them, and they don't know if their husbands will be helpful or not.

IP: She is telling that earlier there has been other foreigners and they have been giving donations, but they might not be used properly. So, Nepalis thinks that when foreigners come the dollar will come (laughing).

I: Does she and her child have any relation to PFPID?

IP: No.

IP: So, she thinks that her child was born normal, but after one-year black magic happened to her.

I: Which caste is she from?

IP Nair.

IP She is telling that earlier they have given them bags and pens and copies. They have given that to all students, so she also got one bag. The volunteers. So, now she will try to bring her child to the day-care centre, but now she is also a little worried.

### 10.10 Interview with Nisu

I: Will you please introduce yourself with name, age, caste and education?

IP: Her name is ... she is 31 years old and she lives in ... and she works here as a helper, and she has studied until grade ten.

I: What caste is she?

IP: Nair.

I: Will you introduce your child also?

IP: Her child's name is ... and she is ten years old and she says that when she was baby she walked late, so she did not walk as other children, but they told her that she would gradually walk, so at the age of four they thought that something was wrong, so they took her to hospital, but doctor said everything was fine, she will just be talking lately. So, if she is deaf or blind that is why she will not talk. Doctor said everything was fine but last year there was a doctor survey where doctor came and checked, and that time doctor said that the function of brain is less than others. When she gave birth to her, she didn't cry and at six month she was sick, and she was suffering from typhus. When she gave birth, she (the baby) didn't cry so people say that's why this happened to her. Until seven years she didn't know about toileting but now she does.

I: Why is people saying the stuff about the fact that she didn't cry at birth?

IP: They are saying that is why her brain is not working properly.

I: What does your child do in the daytime?

IP: In the daytime her activities are very strong. She bites other children and sometimes she pulls the hair of others and trough stuff. And at home they have han and she catch the neck (laughing). That is her daytime activities.

I: Who takes care of your child?

IP: She is the only one who takes care of her and she has one son who is six years, but he is normal, and she is the only one that takes care.

I: Is she married?

IP: Yes, but her husband does driving so he is not home much, but when he is he also takes care.

I: What kind of challenges does your child meet in relation to health?

IP: She is getting sick usually with fever and all and she's having problem with her tonsils. So, she suffers from that. When she is not sick, she does all the things like roughing and stuff, but when she is sick, she sleeps all the time and she don't even drink water.

I: What kind of challenges does your child meet in relation to education?

IP: Her child is not getting the things in her mind. When she says A she jumps to M so she don't understand the letters and the educations.

I: So, she did not go to any school?

IP: First she was sent to the normal school there she used to hit other friends and then the teachers called them and said, "take her to the special school, she should not be in this kind of school".

I: What kind of school is that? Is it the day-care centre?

IP: Yes. There is no other school in this area.

I: Do you have access to facilities and services that helps your child?

IP: She is not known to that kind of services. She is in a blue card, so she used to get 600 now it has increased to 1600.

I: What kind of facilities would you like to have?

IP: She would like her child to talk nicely so a good education where she can learn to speak nicely. She also thinks that 1600 is not enough for her child, so she would like that to increase.

I: What does she use the money for?

IP: One year earlier this day-care centre also used to take 2000 monthly. So many parents didn't take their children to the day-care centre, but in one year they have not taken the money. She spends the 1600 in food and cloth.

I: So, who is supporting the day-care centre now?

IP: There is a donation from outside, but they don't know from where.

I: Is she also getting paid to work as a helper here?

IP: She gets 5000 per month.

I: Does she also get other services from the card except from the money?

IP: She is not using that because when she is sick, she takes her to the medical, the pharmacy stores, so she is familiar. She doesn't know how the card works.

I: Do you get any other support from the government except from the card?

IP: No.

I: How do you experience the way people look at your child?

IP: She says that the relatives and the neighbours used to say that there is no one like her in the whole world. "Why did you give birth to this kind of girl?" Her parents also used to say, "take good care of her and give her treatment and make her nice" "What kind of daughter do you have?". That are the things they say to her.

I: So, they are shaming her for not having a normal child?

IP: Yes, her relatives says that "in all these years we do not have children like this, why do you have?".

I: So, they are not accepting her?

IP: No.

I: So how does strangers look at her child?

IP: Strangers behave okay because they don't know about her diagnose.

I: What do you think is needed for your child to feel included in community?

IP: She don't know.

I: How would you like the future of your child to be?

IP: She would like the future to be bright but how she does not know. She is worried about future, because she is worried how others will react when she is not there. So, she wishes that she can do daily activities by herself.

I: Do you have any relation to PFPID?

IP: No.

IP: She is also worried about her getting her period.

I: We heard that some people put their child away when they have their period. How is that here?

IP: In Brahmin culture they do it but not in hers.

I: So why is she worried about her child getting her period?

IP: She actually don't know what is right and wrong, so if somebody something put poop on the floor, she would eat it and play with it. So, after getting period who will take care of blood and all. If she has to around in the village alone who will take care? That is very dangerous. She is worried about that also.

### 10.11 Interview with Liv

I: Will you please introduce yourself with name, age, job and caste?

IP: Her name is ... and she is 44 years old and she lives here same place chautara and she works here, this is her shop and her education is to tenth grade.

I: Will you please introduce your child with name, age and diagnosis or condition?

IP: So his name is ... and he is 25 years old and he has silver syndrome disorder that means that in the brain there is a hole.

I: What does your child do in the daytime?

IP: He sit here in the day in the shop sometimes in a wheelchair and sometimes just here.

I: Who takes care of your child?

IP: So all the family members take care of him. He has one brother and one sister, little brother and sister and mom and dad, so the fire take care and sometimes the nearby shop and the neighbors they also come here and help him in the wheelchair. So they help each other to take care.

I: What kind of challenges does your child meet in relation to health?

IP: He has a skin disease, like that (points at his hand).

I: What kind of challenges does your child meet in relation to education?

IP: They are saying that they do not have school for him because they have to take to the school and come back, so school also do not wants to take, so they do not have proper school. So it is not possible for them to go to the school.

I: Do you have access to facilities and services that helps your child?

IP: They have a red card, so he gets 3000 pr. month. They do not take services of the card they only take the 3000 pr. month.

I: What kind of facilities would you like to have?

IP: They want school facilities. They need a special school and transportation.

I: Do you get any support from the government?

IP: No, only the 3000.

I: How do you experience the way people look at your child with intellectual disabilities?

IP: No experience, no bad experience.

I: What do you think is needed for you and your child to feel included in community?

IP: So, she is saying that there are no any places that he has not been to, so he is included. She thinks that he is included.

I: How would you like the future of your child to be?

IP: She feel that after his parents leave, she wants him to be like now.

I: What is your relation to PFPID?

IP: She is the president of this PFPID in sindhupalchowk so she knows (everybody is laughing)

I: Why do you think that your child got this disease?

IP: So, when she was pregnant she do not eat salt because of the kidney disease, so she thinks because of that because of the iron problem, this problem happened, she thinks that.

### 10.12 Interview with Sona

I: Will you please introduce yourself with name, age, job, education and caste?

IP: So, her name is ... and she is 31 years old and she is a teacher and she lives in same place chautara and her cast is shrestha Newar.

I: Will you please introduce your child with name, age and diagnosis or condition?

IP: She is... her name is ... and her age is 10 years old and she is a intellectual disability child.

I: What does your child do in the daytime?

IP: So she says that she take her child to the daycare center in the daytime expect Saturday every day.

I: Who takes care of your child?

IP: She is the one after daycare center she takes care of her child.

I: What kind of challenges does your child meet in relation to health?

IP: So earlier she used to have seizure now she is taking the medicine so now she is under control. So now she does not have any difficulties.

I: What kind of challenges does your child meet in relation to education?

IP: She does not understand the education she does not understand all the letter and as you have seen (refers to the meeting with her child at the daycare center earlier that day). She does not also not recognize her mother. So she does not give responders to the thing so the education sector also she is not doing good.

I: Do you have access to facilities and services that helps your child?

IP: She also have the red card and she got 3000 pr. month other than that she does not have any facilities.

I: Do you use the free bus?

IP: No

I: Do you get any support from the government?

IP: No, she said.

I: How do you experience the way people look at your child with intellectual disabilities?

IP: No, no bad experience

I: What do you think is needed for you and your child to feel included in community?

IP: She does not know

I: How would you like the future of your child to be?

IP: She feels that if she is not there after her dead also, she feels there should be one daycare center who takes care of her child, the food and all the facilities she should get, so she feels there should be one daycare center for her caring. So she do not have to take care of her when they get old, so when she cannot do it anymore.

I: What is your relation to PFPID?

IP: She is the second president (everybody is laughing)

I: Why do you think that your child got this disease?

IP: She do not know the reason.

I: Is she married?

IP: Yes, she is. She has to other sons.

I: How old are they?

IP: Elder is 13 and younger is 2 years.

### 10.13 Interview with Ansu

IP: So she is the grandmother of the child. There are two boys, one of them is 13 and the other one is 12 years old. Their parents are also intellectually disabled. So she is the one who is raising the boys now. So we are going to interview her. She is saying that the mother can do her work herself, but the dad cannot. She has to order to do the things, like "do this, do that". He also don't recognize the money and they have the two sons. She is taking care of the two sons and the parents also.

I: Which one of the parents is your child?

IP: Her own son is the one with intellectual disability. Her son married to another intellectual disabled.

I: Will you please introduce yourself with name, age, job and caste?

IP: Her name is ... and she is 65 years old. She lives in ward number 4. Her job is doing agriculture and household work. She is a cancer patient, so she has got the breast cancer. She have cut one breast due to the cancer. Now her daily life is taking care of the children and the parents also. The intellectually disabled parents.

I: Will you please introduce your child, his wife and also grandchildren?

IP: Her sons name is ... and he is 44 years old. His wife is ... and is 27 years old. Their first son, older one, is named ... and is 15 years old. And then the younger is ... and is 12 years old. They are all suffering from intellectual disability. She said that the father used to eat soil in his childhood, so that is the reason he is suffering from intellectual disability.

I: What are they doing in the daytime?

IP: So in the daytime the father and mother works in the agriculture and the milk, but one have to be with them like saying "you do this, you pluck, you cut the grass" and they have to say "come back to the home" also. They don't know that after finishing the work they have to come back to the home. For the son one have to be there ordering him "do this, do that", but the mother does her work. She don't need ordering, but she is also slow, not like we are normal. The two children where the elder is the same as the father, so he don't understand that he has to return back and all. The younger is a little bit sense that he can come back, but it is very late. He don't understand like he goes and he have to come back. After so many times and after so many minutes he knows that he has to go back, and he will come back. They both goes in school, but it is just like they goes in the school. They used to tear the books and the copies and bite the pencils and all. So

she was saying that they spend so much money in the books, but now there is none of the books. They tore all of them.

I: Okay, so they are not really learning anything in school? They are just going?

IP: Yes. And the sister brought them here, because she thought that the love of the grandmother and grandfather are making them not learning, so she put them in a hostel. In the hostel in 3 months the teacher says "you have to take them to the special schools". In the three months they are taking out from the schools.

I: In three months from now?

IP: No. In three months.

I: So they have been out of school for three months?

IP: Yes.

I: So are you going to send them to a special school or will they stay in the normal school?

IP: They have searched a lot in Kathmandu also, but they have not found and at last they saw the same school they have gone. So now they are in the normal school, because they didn't find a school there. In Kathmandu also they didn't find.

I: Okay...

IP: They are saying that they can't leave them alone, because if they leave them they will tear the furniture and in the TV remote they have also taken all the buttons and eaten. If they find a blade they will tear all the cushions and the blankets. The food also they will not know how much the stomach wants. So if they are given this much also is okay, if you give larger amount they will eat all. So they don't know the difference.

I: Is it only you taking care of the children or is anyone else taking care of them?

IP: She is the one who is taking care and the grandfather also. The wife also cooks food and wash clothes, but she also doesn't know how many amount of food should be good. There should be for tomorrow also, but she don't know that. She cooks all the food, but not like good as us, but she cook the food. She can take care of her child and her husband. She also knows the money and she also know the calculation. How much to return and how much to take back.

I: Okay...

IP: She is saying that if one of the teachers will show and they will give a biscuit, they will not eat. But when there is not teachers or elders they start to do rough stuff like breaking stuff and cutting. In front of teachers they act like they are very good. Also if they will see the button of the dress they will start biting the dress. Everything when they see, they will bite.

I: What kind of challenges do they meet in relation to health?

IP: The father when he was three years old he ate a lot of soil, so he was sick and he was taken to the Kathmandu hospital. From his stomach the worms are taken out, a large amount of worms were taken out. After he used to vomit every day. Now he also vomits every day. Also normal fever and headache happens in a month, but vomiting he does every day. The mother has migraine. The elder son also vomits.

I: Do you know why the mother and son have their disease?

IP: They don't know why they are vomiting, but she is saying that they will say "I have a headache" and sleep and after wake up. If she is in the home she will give some food and then they eat. If there is nobody they don't have food all the daytime and night also.

I: Okay...

IP: They don't know what amount of food they have to eat. If there is a banana or like 50 bananas they want to eat at one time. If they say "stop, don't eat", they don't listen and they will eat all the bananas.

I: Okay...

IP: She is saying that the father also don't know what amount of food they need to eat, and the children also. They can eat 3 apples and 10 bananas at one time.

I: What kind of challenges do they meet in relation to education?

IP: The father is the same like the two sons. He has also gone to the school but nothing comes in the head, so he also cancelled the school. In that time there used to be only one school. That is also a boarding school and not special school. So he haven't and the mother studied till third grade. The children are now both going to the normal school, but it is just like going and coming. Nothing improving.

I: Do you have access to facilities or services that helps the children?

IP: Because they both talk nicely they don't have the card. They have card, but they don't get any facilities or any money.

I: Can you use the card for the bus?

IP: No.

I: Which kind of card is it?

IP: White.

I: So you don't get any support from the government at all?

IP: No. From other also they don't get any facilities and services.

I: What kind of facilities would they like to have?

IP: She feels like there should be a good education system in her village, so she don't have to go to the far place. Her grandsons if they learn and study, that would be the great successful things for her.

I: Okay...

IP: She is saying that she has a big tension about the grandchildren. She thinks that other may affect or unhamper them and in school also some they touch and others they beat. Teachers also told her "don't send your grandson to the school, because we cannot teach them". So now she is tense about the grandchildren and she wish if there was a special school nearby the village or even in Chautara. That will be grateful for her.

I: How do you experience the way that people look at your son and grandchildren?

IP: She is saying that there is a festival and marriage ceremony, so many ceremonies we have, so they have been invited but still they don't get the food, because they don't know that they have to go there and take the food. Somebody will not come to give them the food. So they will be empty stomach and in the agriculture also you have to cut the plates of the soil to flow the water. She will say "go and cut the plates of the soil", and other neighbors and relatives will them come and say "why you cut the plates" and start harassing and beating. When grassing the cows also, the father and the son will take the cows and the cows of other neighbors will eat the grains and rice. They will come and say that the fathers and his cows have been eating the grains, so they have to pay back. Even though the cows haven been eating it, they will still say like that.

It has been three years that the relatives have been saying "who will be working for them? We are not the workers of them". So they are saying like that.

I: So people are having a kind of negative attitude towards them?

IP: Yes. In the school also the grandchildren goes and other people will tell them to buy something like pens, chocolate or noodles and they go out of the school. The teachers will say "why you are out of the school?", and the one who have said to go, they say "we haven't send". So they will get beatings. If others also start fighting with them, the teachers don't care about that also. The teacher ignores. So I think in the school also they are getting ignorance from the teachers.

I: What do you think is needed for the children to feel included in community?

IP: What she is saying is in the school also the facilities that comes is not given to the grandchildren. They are given to the talented students and the normal students. It should be equal to all and there should be strict regulation. Rules and regulation should be followed. There should be equal rules and regulations to all. Again there should be a special school nearby so that she will be happy and be in peace seeing that their grandchild is in the good hands.

I: Okay, so how would you like the future of your grandchildren to be?

IP: The same.

I: Do you have any relation to PFPID?

IP: No.

I: I was wondering about something you said in the beginning. If the wife is 27 years old now and the oldest son is 15, did she give birth when she was 12?

IP: She is 31. She is guessing the age.

I: Okay, was the marriage arranged?

IP: Yes arranged.

### 10.14 Interview with Prati

I: Will you please introduce yourself with name, age, job and caste?

IP: She is ... from Chautara, 31 years old and she is a housewife. She studied till grade three.

I: Will you please introduce your child?

IP: Her name is ... and she is 7 years old. When she was 1 years old she started shivering, so she used to shiver one leg only, so they have gone for the checking in the doctors. The doctor says everything is normal, so she think one leg might be the weak, and that is why she i shivering. When she was 3 years old they admitted her in the school, boarding school, but she was not able to write the letters. The teachers said "it's normal, she will start writing", but one of the teachers said "I think it is not normal, you might feel bad, but you should take her to the daycare centre". Then she took her to the daycare centre. There was the one girl in the centre...

I: Yes, the one that was drawing?

IP: Yes.

I: So what does your child normally do in the daytime?

IP: In the daytime she goes to the daycare centre. In other times she plays in her own world. If they are walking in the road, she goes straight. If the mother sometimes tries to turn, she will get angry. She has a brother, and she fight with the brother and pulls hair. Her brother is small. Her brother is two years old and she pulls his hair. People used to say "you have that daughter, because you have done some sin and some bad things", so she feels bad hearing that things.

I: Okay, so that is how people look at her child?

IP: Yes.

I: Is it strangers or family?

IP: The relatives used to say that. The 2 year old brother helps and tells to wear trousers to the sister, but she doesn't know how to wear the trousers. Her relatives tell her that she have done some sin, and that is why she has a child like that. She have one big sister also who is 9 years old and she started in third grade, but she is always in her own dream and in her own world doing her own things like that.

I: When she is not at the daycare center, who then takes care of your child?

IP: She herself takes care of her child.

I: Do you have a husband?

IP: Her husband don't take care of the child. She is the one who takes care of her child.

I: What kind of challenges does your child meet in relation to health?

IP: She has a fever usually and when she has that she shivers. That is only the sickness she has. Not large.

I: What kind of challenges does your child meet in relation to education?

IP: She is saying that her daughter doesn't study. The letters does not go in her head. She forcefully send her to the boarding school, but the teacher complained that she opens her clothes and sleeps naked. So there is a problem, so she can't take her in the school.

I: Do you have access to facilities and services that helps your child?

IP: Her father in law is government officer in this district, so he said "the daughter is not disabled, so why do you need a card?". So he didn't make the card. He didn't write the letter to make a card.

I: So he doesn't accept that the child is disabled?

IP: No.

I: What kind of facilities would you like to have?

IP: The daughter is a girl, so she feels like if she could take care of herself, that would be the best. Also if she could study a little bit, that would be a good thing. Her requirement is also a special school in Chautara, so she can learn.

I: What do you think is needed for your child to feel included in community?

IP: There should be good rules and regulations. Equal for all.

I: How would you like the future of your child to be?

IP: She dreams that her daughter can do her work herself. Can dress herself. Can do her daily work herself.  
She dreams that her future she be like that.

I: So you dream about your child becoming more independent?

IP: Yes.

I: Okay...

IP: She is saying that the principal of the earlier boarding school, when the daughter was coming back she was crying, so the principal told the mom that "you absence the school and that is why leave the nearest school and went to the far school, then this will happen. The daughter will cry". So she got angry, because their teachers said that they can't teach your daughter, and she should take her to the special school. So she got angry and she said that "your teachers told to take the kid to the special school, so why you are saying that".

I: Do you have any relation to PFPID?

IP: No.

I: Do you also believe that your child got the disease because of a sin committed in former life or is it only your relatives that believes that?

IP: She doesn't believe that. It is only the relatives.

## **10.15 Observations**

### **Observations from daycare centre**

The daycare centre is located along a road on a small hill in the mountains. There is almost nothing in this area and there are no neighbours to the daycare centre. The house of the daycare centre is very small and there is only a kitchen and a playroom. The playroom contains of two daybeds, a table with two chairs and a rib. There is also a scheme on the wall and drawings hanging from the ceiling by strings.

When we arrived, there were already two children in the centre. Right now, there is only one helper for the two children, which is why one of the two girls are loosely bound to a chair in front of a mirror to make sure that she does not walk away from the centre. The bound girl is making sounds with her mouth and seems pretty underdeveloped. The helper is more concentrated about the other girl on the floor. She is training her by reading books and singing songs. One of the melodies sounds like itsy bitsy spider.

In total there are to staff members who takes care of the children. Our interpreter tells us that both girls are 10-11 years old and that the girl in front of the mirror cannot even recognize her parents. The girl on the floor (the one singing) seems like she is registering her surroundings and is waving at us.

Now one of the helpers are massaging the hands of the girl who sits in front of the mirror. The interpreter tells us, that the girl on the floor (reading and singing with the teacher) could not for example go to the bathroom by herself before she came to the centre. This she was taught by the centre.

Another girl arrives with her mother. The girl has been given candy by her mother. She is holding her mother's hand until she has to leave.

We are told that the parents deliver their children at 10 am and pick them up again in the evening. Most of the parents are living only 15 minutes away from the daycare centre. Normally they have 17 children, but today they are not that many because of the festival (Nepalese holiday). It is almost 11.30 am and now another girl is arriving at the centre. The mother of the child stays. It looks like the girl has Down syndrome, but she is capable of communicating orally.

### **Observations from interview with Amita**

We are sitting in the kitchen of the day-care centre on some really small chairs. Our translator tells the interview person about us and our purpose. The interview person/the mother has tika (the red dot, that indicates

that she is hindu). The mother is very smiley and uses her arms a lot to communicate. She answers very fast and it seems like she has a lot on her mind.

#### **Observations from interview with Nisu**

The mother works at the day-care centre. She is laughing a lot while answering the questions. She tells that her child has some problems with her tonsils and therefore she is touching her throat while explaining.

#### **Observations from interview with Liv**

We are sitting in a shop, where they sell fabrics. Present are the mother (the interview person) and her son, who is spas ticking. The mother is not very concentrated and is sitting on her phone while we are interviewing. There is a lot of noise from the road, and there is also a lot of customers in the shop. It is also disruptive that the son is there while we are doing the interview, as he often outbreaks, which is disturbing. The mother also talks to the son while the interview is going on. During the interview a male shows up in front of the shop and he is staring at the son. Our guide sometimes also disturbs when she just starts talking.

#### **Observations from interview with Sona**

We are still sitting in the same shop and suddenly another mother shows up to get interviewed. She would like to be interviewed at the same place even though there is a lot of other people in the shop. We are still sitting on the floor and on piles of fabric.

#### **Observations from interview with Ansu**

We come into a house and walk up to a room where we are sitting on chairs facing each other. The house looks like it is a middle-class home, as we have seen them here in Nepal. The grandmother to the children is the one who is taking care of them and that is why we are interviewing her. The daughter of the grandmother answers often on her behalf.

#### **Observations from interview with Prati**

We are continuing the interview at the same house and in the same room with another mother. The mother is sitting on the floor. She is very young. Under the interview a lot of women are entering the room. They are commenting on Nepali and sometimes it seems like they are discussing the questions that we are asking. Sometimes they also interrupt the interview. At the end of the interview there are 6 other women in the room besides us and our translator.

**General experiences**

In general, the mothers seem happy and they are very willing to speak about their children.

### **10.16 Personal evaluations**

#### **Caroline**

In general, the elaboration of this project has been a positive experience as I have had the opportunity to test my sociological skills in a totally different country and environment with a different culture. Moreover, it has been interesting to look into a new field of a minority who has completely different conditions than in Denmark. However, these cultural differences have given some challenges especially in relation to collection of data, such as linguistic misunderstandings in interview situations, but these challenges have for sure been a good learning experience.

The dynamics of the group has all in all been great as we have been working together previously. This means that we are familiar with each other's strengths and weaknesses, and therefore we have been able to support each other in challenging situations. Within the group we have all been motivated to work with this project. This was caused by the fact that we have had the feeling of this project being useful for the NGO that we have been collaborating with, and moreover useful according to improve the life conditions of people with intellectual disabilities.

Overall this project has been a great experience and learning as I personally have been tried in using sociological methods in a different cultural context.

#### **Julie**

Last semester the semester project was also draw in this study group which means that we have knowledge about each other's strengths and weaknesses. Overall, I think that the drafting of this project has went well considered all the challenges. These challenges are connected to being in intern and doing a research in another country which has a different culture. We have all worked well together in the whole process and in relation to that we have written most of the project together. I see this as an advantage as everybody than gets involved in every part of the project.

For me it has been a challenge not only to write the project in English but also to conduct the interviews in English too. I feel that it has been a challenge for us all, but we have been very good at helping and complement each other in the process. Even though it has been challenging I see it as a very good experience as I am well aware that the candidate that I am going to study afterwards is going to be in English. It has also been challenging to draw this project because of the cultural differences. It has been necessary to

adjust our working process to the Nepalese culture which has been challenging. To get so close to the Nepalese culture has on the other hand also been a amazing experience that cannot be compared with anything else. Furthermore, I find the subject human rights very interesting and, in that relation, it has been exciting to work with human rights in another country.

Overall the drafting of this project has been a really good and educational process. I think we in cooperation have achieved a really good result.

### **Tina**

This semester the preparation of the project has been very different from what I am used. The fact that the project had to be written in English has been a challenge, but at the same time very educational. Because of this, we have written the whole project together, as we wanted to make sure that everyone agreed on the phrasing. Moreover, we have been exposed to more time pressure this time as we were collaborating with the organization where we were doing our internship. The internship already finished on November 9th, 2019, and therefore it was necessary to plan and structure our time very well due to the short timeframe. This was done very successfully. Academically my skills were also challenged by the different culture and the language barrier but in a positive way. It has been rewarding that we were friends beforehand, as we often were exposed to unfamiliar situations, where it was important to support each other - both academically and as friends. Overall, I think that we ended up with a very good product considering the circumstances.