



Federal Ministry  
for Economic Cooperation  
and Development

# REPORT ON BASE LINE SURVEY

Project P5087 Including the Excluded Project

## Abstract

This report highlights the prevalence of disability, availability of health and Rehabilitation services for persons with disability, educational and socioeconomic status of persons with disability in Nawalparasi district (Susta Purba) Nepal. This is an outcome of a baseline study carried out by Kopila Nepal as part of the project “Including the Excluded” finically supported by Federal Ministry of Economic Co-operation and Development of the Government of Republic of Germany and German Leprosy and TB Relief Association (GLRA).

Prakash Raj Wagle  
Prakaash.wagle@gmail.com

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## List of Abbreviations

BMZ	-	Federal Ministry for Economic Co-operation and Development
CBID	-	Community-Based Inclusive Development
CBR	-	Community Based Rehabilitation
DPOs	-	Disabled People's Organisations
GLRA	-	German Leprosy and TB Relief Association
LDC	-	Least Developed Country
MoPR	-	Ministry of Peace and Reconstruction
MoWCSC	-	Ministry of Women Children and Senior Citizen
MoHP	-	Ministry of Health and Population
NFDN	-	National Federation of the Disabled Nepal
UNCRPD	-	United Nations Convention on the Rights of Persons with Disabilities
WHO	-	World Health Organisation

## Background

Nepal has gone through major political changes in the last two decades. With the end of 240 years, long Monarchy and centralized, the political structure of the country has been converted to the Federal Democratic Republic and a secular state. Nepal is now divided into seven provinces and 753 local municipalities. Each local unit is composed of wards. There are 6,743 wards in total. The local governments enjoy executive and legislative as well as limited judicial powers in their local jurisdiction.

Nepal is a Least Developed Country (LDC) with a Human Development Index of 142 out of 189 for 2019<sup>1</sup>. The current population of Nepal is 28 million<sup>2</sup> which is expected to grow steadily to 33 million by 2030<sup>3</sup>. The Terai region make up 50% of the population with 43% residing in the hills and 7% in the mountains. Nepal is a multicultural and multiethnic country, home to 125 distinct ethnic groups, speaking 123 different mother tongues<sup>4</sup> and following several indigenous and folk religions in addition to Hinduism (81.3%), Buddhism (9%), Islam (4.4%), Kirant (3%), and Christian (1.4%). Nepal is a low-income country where 34% of the population are multidimensionally poor and an additional 22% are classified as vulnerable to multidimensional poverty (2016 estimate)<sup>1</sup>. The country experienced internal conflict for 10 years from 1996 to 2006.

## Disability in Nepal

Disability prevalence in Nepal is 1.94% of the population (Census 2011) in which the percentage of males and females is 2.18 and 1.71 respectively. It is 3.6% as per Nepal Living Standard Survey (2011). Based on SINTEF (2016) report which used the Washington Disability Group questionnaire on 'functioning', disability prevalence is estimated to be 2-4% with severe difficulty in daily functioning and 9-13% with some functional difficulty. Between 1996 and 2006, an internal conflict which was mostly in the hills and western parts of the country left over 13,000 people dead. Nepal Peace Trust Fund (NPTF) under the Ministry of Peace and Reconciliation/Reconstruction (MoPR) was established in 2007. It has recorded a total of 7,164 people with disabilities affected by that conflict in Nepal. (source: MoPR). The April 2015 Nepal Earthquake killed nearly 8,970 people and injured nearly 22,302. 28 people died & 1110 people were injured in a windstorm that occurred on 31<sup>st</sup> Mar 2019 at Bara and Parsa of Province 2. (source: DRR Portal, MoHA).

The government of Nepal is a party to the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) and has promulgated the Disability Rights Act-2017 and Regulation 2020 in line with the convention. Ministry of Women, Children and Senior Citizens (MWCSC) is the country's focal point for disability affairs and overall rehabilitation. Under this ministry, there are government CBR programs implemented through the local bodies/municipalities. These CBR programs at the

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<sup>1</sup>[http://hdr.undp.org/sites/all/themes/hdr\\_theme/country-notes/NPL.pdf](http://hdr.undp.org/sites/all/themes/hdr_theme/country-notes/NPL.pdf) accessed on March 3, 2021

<sup>2</sup> <https://data.worldbank.org/indicator/SP.POP.TOTL?locations=NP> accessed on March 3, 2021

<sup>3</sup> Central Bureau of Statistics. National Population and Housing Census 2011 (Population Projection 2011-31). Kathmandu: Central Bureau of Statistics, 2014.

<sup>4</sup> Ibid

local level engage with the local DPOs to conduct a range of activities across the WHO CBR matrix. There are several other rules, regulations and directives that include people with disabilities at various levels. Nevertheless, effective implementation of those acts, policies and plans is a major challenge.

The disability rights movement in Nepal is growing with strong advocacy from the National Federation of the Disabled Nepal (NFDN), an umbrella organization of more than three hundred organisations spread all over the country. Disability support services including assistive devices provision and health-related rehabilitation are being provided in partnership with non-government organisations. The government also provides direct financial support to a few NGOs and physical rehabilitation centers.

## The Including the Excluded Project

With the financial support from BMZ, GLRA Germany, KOPILA Nepal has been implementing the “Including the Excluded”, a Community Based Inclusive Development Project (CBID) for the rehabilitation and social inclusion of Persons with Disabilities in eight municipalities of Nawalparasi district. Nawalparasi (east) is a new district created by dividing earlier Nawalparasi districts as east Nawalparasi and west Nawalparasi in 2017. The total population of the district is 302,000 and the district is divided into eight municipalities. Out of 1,426 square kilometers, Around 70 percent of the district is covered by middle hills with the highest peak of 1936 meters and 30 percent is the plain area with the lowest land of 11 meters from the sea level. This shows the geographical diversity of the project area. The Nawalparasi hills are regarded as one of the poorest parts of the Gandaki district mostly resided by Magars and Dalits communities.

The project duration is 38 months and carrying out a baseline study of disability was one of the project activities. As planned the baseline study was carried out in March-April 2021.

## Methodology

A population-based door-to-door survey of persons with disabilities was carried out in Nawalparasi district. The survey was carried out with technical assistance/partnership with Nepal Engineering College Western Regional Campus, **Centre for space science and Geomatics Studies**, Pokhara.

Survey questionnaires were developed based on the guideline provided by the GLRA Asia/India considering the project design and data required for the project. Based on the questionnaires a mobile application was developed using Kobo Toolbox to collect information. Forty volunteers from eight municipalities were provided two days of training on disability identification and collecting data of persons with disabilities using the mobile application. The enumerators could collect data offline and at the end of the day when they returned home and get online, the collected data would automatically be transferred to the server that was established in Pokhara. In such a way every day monitoring of the work was possible. A messenger group was created where enumerators could post the problems encountered during the survey and get expert advice. The enumerators were asked to keep location on in their mobile to make sure that they were exactly in the home of persons with disabilities when collecting information. A review meeting in the middle of the study was carried out and at the end, when data collection was over feedback was collection meeting was organised with the enumerators.

## Scope and limitations

The scope of the baseline study was to find the actual number of persons with disabilities and their access and participation in health including rehabilitation, education, livelihood and social aspects in Nawalparasi district. It was found that the volunteers had difficulty to identify unseen disabilities e.g. autism, mild intellectual disability and psychosocial disability. An online support mechanism was established where volunteer could post their problems and get advice from the experts which was helpful to a greater extent but it was difficult to diagnose disability remotely. Therefore, it has been realised that some invisible persons with disabilities have been left. Some families did not want to disclose the disability of their child and therefore, could not count them in the survey and some persons with disabilities voluntarily did not want to participate in the survey.

## Data Analysis

The data was collected using a customized mobile application. A server was established in Pokhara where the data collected every day was stored as per the category. The analysis was made using the Kobo toolbox. The questionnaires were developed in Nepali and all data was collected in the Nepali language and translated into English.

## Findings

### Total number of persons with disabilities

The baseline study found 6,193 persons with disabilities in the Nawalparasi district which is 2% of the total population. Out of which 3543 (57.20%) are male, 2645 (42.70%) are female and 5 persons were identified as the third gender. The finding is close to national disability data of 1.94% as reported by population census 2011 but the percentage of males and females with disabilities in our finding is different than the national survey. The national population survey 2011 reported 54.66% males with disabilities and 45.44 females with disabilities. The low number of females with disabilities in our survey can be an indication of missing women and girls with disabilities. The finding is far below than reported by WHO and World bank<sup>5</sup>, 15% of the total population. It is mainly because we used the definition and classification of disability made by the government of Nepal which is based on the impairment, not functionality. Furthermore, some people voluntarily denied being involved in the baseline survey. As mentioned in the limitation people with unseen disabilities i.e. autism, mild intellectual disability and psychosocial disability was difficult to identify by the volunteers.

Mother and wife are the main caretakers of persons with disabilities 26.48% of persons reported that the mother is taking care of the person whereas 20.45% reported that the wife is the caretaker. The same number of people reported that there is no one as caretaker but it is the joint responsibility of the family members and the rest mentioned father, son, or daughter as caretakers of persons with disabilities. This indicates that caring responsibility mainly lies on female members of the family.

<i>Total number</i>	<i>Male</i>	<i>Percent</i>	<i>Female</i>	<i>Percent</i>	<i>Gender not known</i>
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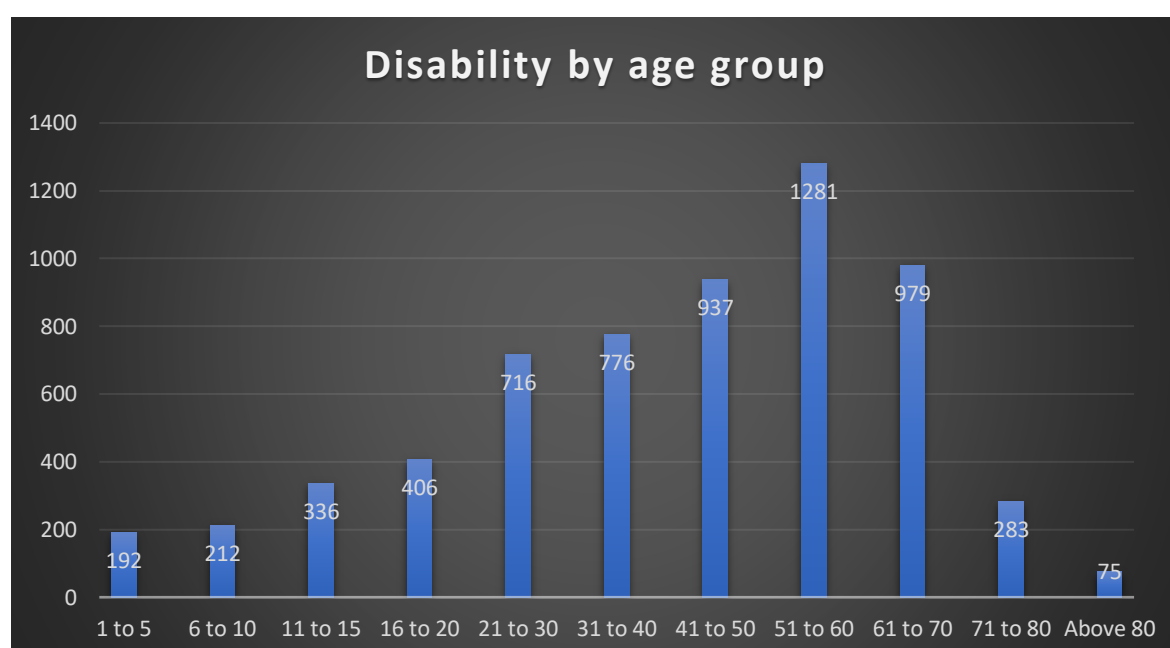
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<sup>5</sup> WHO and World Bank, World Report on Disability 2011

6193	3543	57.20	2645	42.70	05
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### Disability distribution by age group

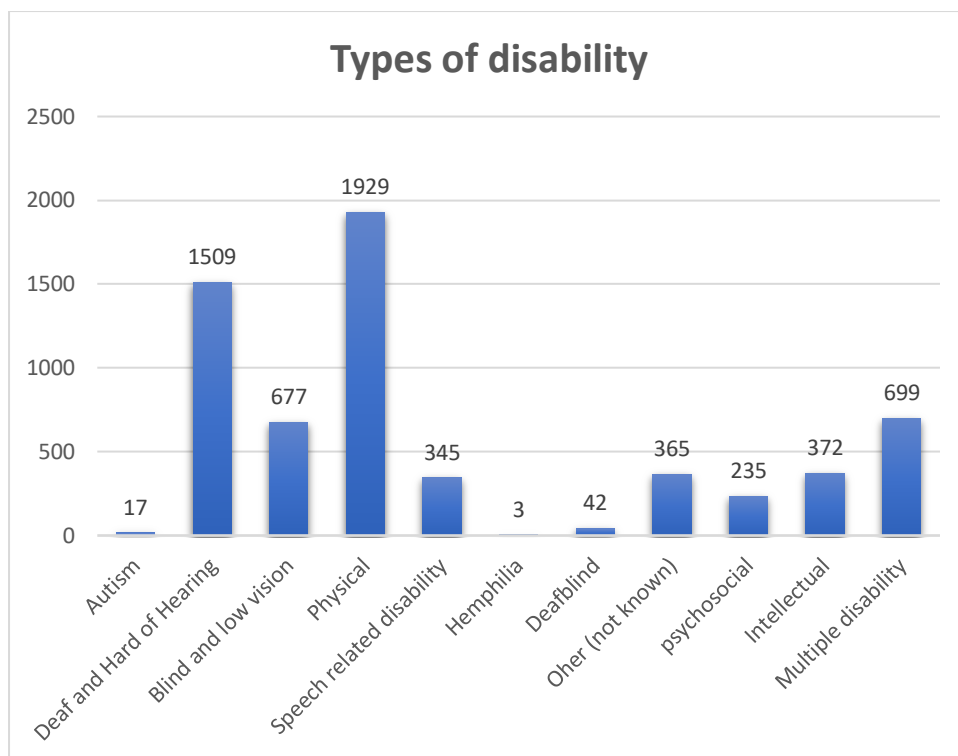
The survey found the highest rate of disability prevalence in the age group of 51 to 60. This information seems to contradict some other studies as childhood disability is reported to be high due to significant congenital deformities and child malnutrition. However, it was noted that the people in the project are consuming high alcohol which might have caused stroke, fall injury is common in the hills. The low number of childhood disabilities also indicates a high mortality rate among children with disabilities and late identification of disability as there are no screening services for children with disabilities.



### Types of disability

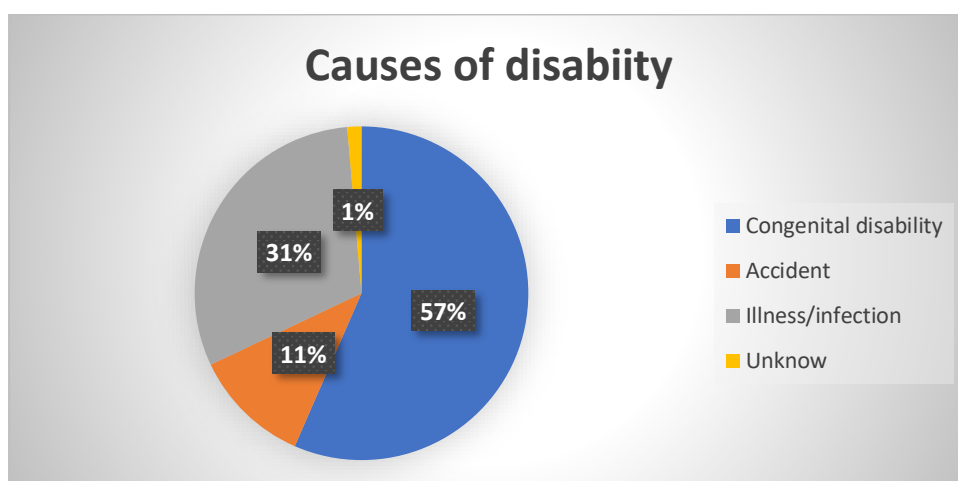
Out of total 31 percent are persons with a physical disability which includes leprosy, amputee, muscular dystrophy, cerebral palsy, spinal cord injury etc. followed by deaf and hard of hearing which is 24 percent and blind and low vision 11 percent. The finding slightly contradicts with the national data which has reported 18.46% to be blind and low vision and 15.45% deaf and hard of hearing<sup>6</sup>. However, Nawalparasi is known to have iodine deficiency and which may be the cause of deafness. The types of disability are presented in the chart below

<sup>6</sup> Kathmandu University, Disability Study Centre, 2017, Disability in Nepal,



### Major causes of disability

More than 50% of disability is by birth followed by illness and accident. This indicates that the prevention of disability is an important area of work in the district. As the district is one of the poorest ones in the province where child malnutrition is reported to be very high. A recent study <sup>7</sup> carried out by Action Against hunger reported overall stunting among children 6-69 months were 25.7% and underweight 28.8% in the district. The same study reported that malnutrition among mothers in the age group of 14-49 was 11.1%.



<sup>7</sup> Action Against Hunger, 2018 Final Report on Nutrition Assessment Nawalparasi Bardaghat Susta East, Nepal



### Access to Rehab Services and Assistive Devices

The survey has revealed that the majority of people do not have access to health and rehabilitation services. A large number of people (73.66%) are not aware if they can benefit from any rehabilitation services. Only 5.46% of people said they have received some services. Most of them reported that they receive those services from private health centre which is expensive. The table below shows the need and the gap of health and rehabilitation services in the district.

<b><i>Health and Rehabilitation Services</i></b>	<b><i>Total number</i></b>	<b><i>percentage</i></b>
<i>Need Health and Rehab Services</i>	1633	26.37
<i>Not aware, if they need Rehab Services</i>	4562	73.66
<i>Received rehab services</i>	338	5.46
<i>Not received any services</i>	5865	94.70

The availability of assistive devices is one of the major issues for persons with disabilities in Nepal. It is estimated that only 10-15% of people who need assistive have access to them in Nepal. In the survey, 878 persons with disabilities reported that they are currently using some type of assistive device and 2846 persons mentioned that they need an assistive device. The following table presents the need for assistive devices as reported by people during the survey.

<i>Crutches</i>	273
<i>Hearing aids</i>	523
<i>Walker</i>	128
<i>Wheelchair</i>	402
<i>White cane</i>	147
<i>Others (to be assessed)</i>	1,373
<i>Total people in need of assistive devices</i>	2,846

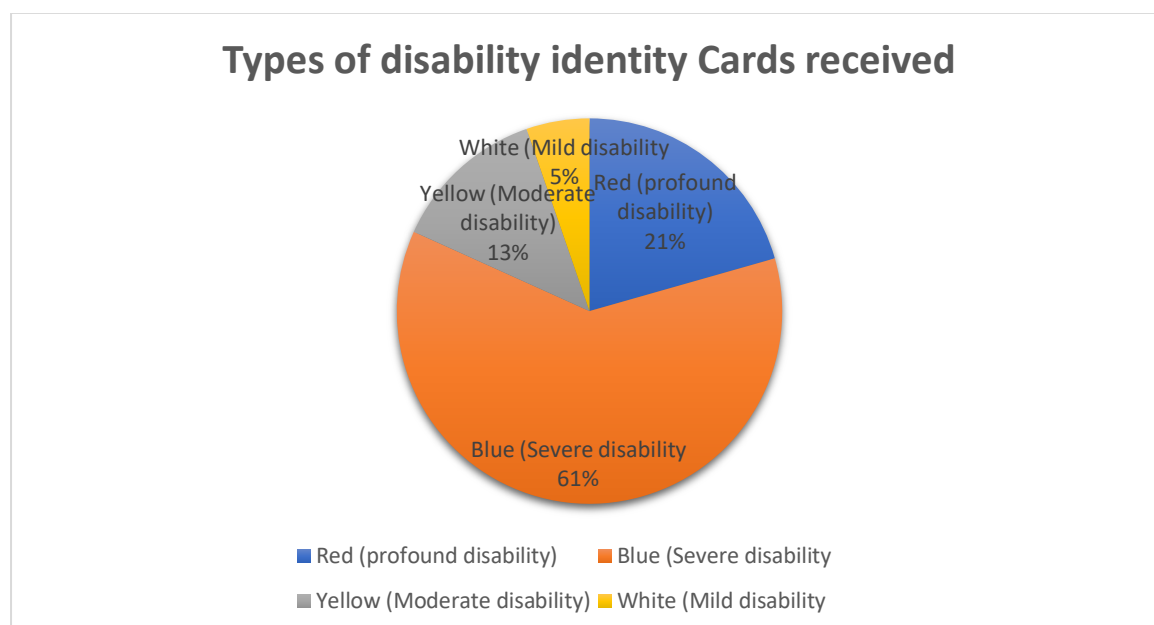
### Status of disability identity card and Citizenship certificate and birth registration

Only 3,419 (55%) persons with disabilities have received disability identity cards and 2774 (45%) have not yet received whereas 81% of persons with disabilities have received citizenship certificates. Similarly, 71.50% of persons with disabilities have birth registration. Almost all adult persons with disabilities have received citizenship certificates. Birth registration was made compulsory by the government of Nepal relatively recently. People born before 1980 generally do not have birth registration in Nepal.

The high number of people not obtaining disability identity cards indicates that the awareness and support to obtain disability identity cards is essential. One of the volunteers reported that in the village there are people who cannot communicate in the Nepali language and therefore, are finding it difficult to get a disability identity card. Furthermore, for many people with a disability traveling to the municipality office to get an identity card is difficult. For some disabilities, they need to get tested i.e. audio test, vision test and IQ test. Mainly the unseen types of disability e.g. autism, intellectual disability, deafness and psychosocial disability have difficulty getting a disability identity

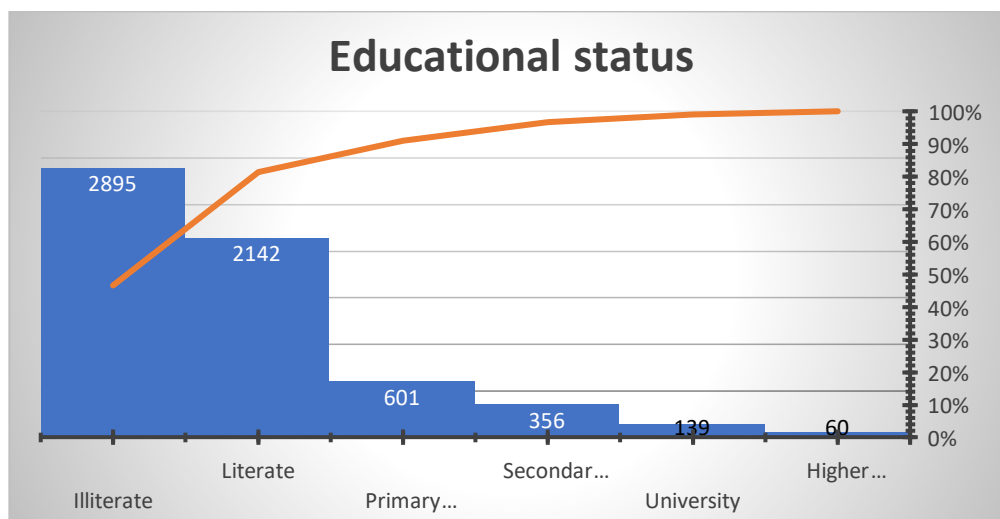
card. Some families of persons with disabilities find it difficult to afford for the test to get a medical certificate before getting a disability identity card.

The government of Nepal provides four different types of disability identity cards based on the severity of their disability. The Red identity cardholders (profound persons with disabilities) receive Rs. 3000 monthly allowance and Blue cardholders (severe) received Rs. 1,600 per month. Yellow and White cardholders are not entitled to any allowance. Therefore, persons with disabilities who fall into the yellow and white card holding category do not have any benefit of getting an identity card. The less number of people receiving yellow and white identity card indicates less attraction of people on those types of the card as do not see any benefit of getting such card. However, most of them seem not aware that there are other social benefits i.e. discount on travel fare, scholarship for study and discount in medical services etc. Details of types of disability cards received are presented in the chart below.



## Educational Status

A large number of persons with disabilities, 46.74% reported to be illiterate in the project area and 34.58% reported to be just literate, 9.70% have completed primary education, 6.71% have got secondary education and 2.24% have received a university education. According to the Flash Report of the government Nepal- 2019, the gross enrolment rate in the primary education in Nepal is 97%. Out of total (97%) enrolment in primary education, which is less than 50% for children with disabilities. There finding reveals that there are 1,000 children with disabilities of school going age (5 to 15 years) in the project area, out of which 518 are currently enrolled in the schools. This indicates that 51% children with disabilities who are in the school going age are enrolled in education. However, we did not include the school enrolment rate of children with disabilities in any particular year. The literature has reported high dropout rate of children with disabilities which was also not included in the survey. The following chart provides information on the educational status of persons with disabilities in the district.



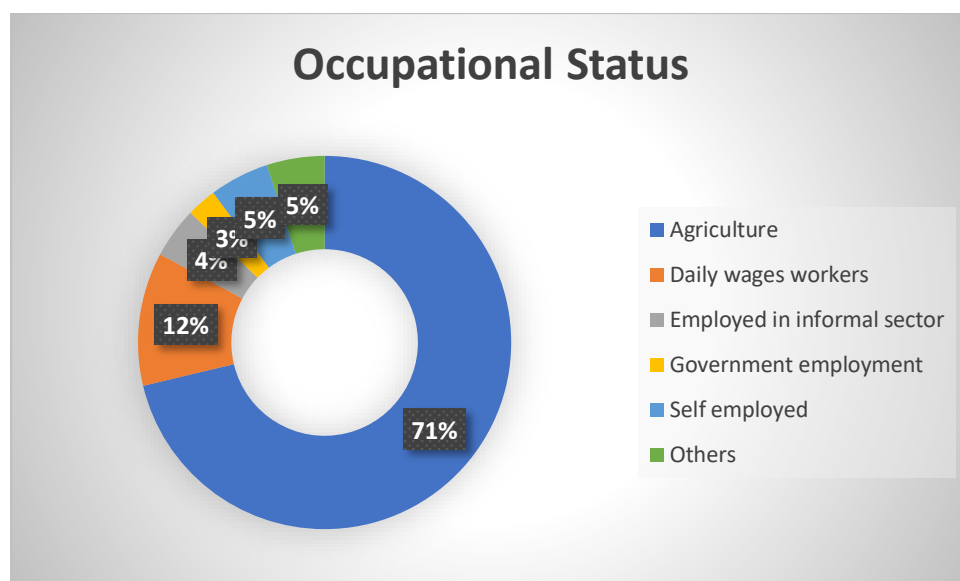
Currently, 491 persons with disabilities are studying in regular school, 27 are in the special school, 66 in the college and 15 persons are getting an education in other types of educational institutions.

### Access and participation in the school

Most of the schools, even in the urban areas are not physically accessible to persons with disabilities. In a question asked to all school-going age children if the school including classroom, library, wash facility accessible to them, 86% of children said that the school is not accessible to them. 95% of students reported that they do not involve in any extracurricular activities in the school and 96% of children with disabilities reported that they are not involved in any child clubs either in the school or in the community. Awareness of and access to scholarships is also low in the community out of school-going-age children only 254 are receiving the scholarship from the Ministry of Education. This reveals that access to education is a huge problem in the project area however, most of the school-going students with disabilities are getting free education but still few of them are paying fees.

### The livelihood of persons with disabilities

A vast majority of persons with disabilities 5025 (81%) reported that they are not involved in any occupation. The other previous studies carried out have also reported that 80% of persons with disabilities are not involved in any productive work in Nepal. This is in line with global estimation made by various agencies and as stated by SDG 2030 that 80% of persons with disabilities live in poverty. Out of 1168 persons with disabilities who are involved in some occupations 71% are involved in agriculture and followed by daily wages workers. The following chart shows the occupational status of persons with disabilities.



It was realized during the survey that many people with disabilities are not aware of their income and families were hesitating to disclose their income. They were asked to provide the estimated monthly income of the family which is presented in the table below.

<i>Monthly income of the family of persons with disabilities</i>	<i>Number</i>	<i>percent</i>
<i>No income or do not know</i>	4318	70
<i>less than 5000</i>	1529	25
<i>5000 to 9000</i>	214	3
<i>10,000 to 14,000</i>	65	1
<i>15,000 to 19,000</i>	33	1
<i>20,000 to 30,000</i>	25	0
<i>31,000 to 40,000</i>	4	0
<i>41,000 to 50,000</i>	2	0
<i>51,000 and more</i>	3	0

### Training and Skill Development

210 persons with disabilities have received basic training on livelihood and income generation mainly in the agriculture sector like chicken keeping, goat keeping, vegetable farming and running small-scale businesses. 2073 persons with disabilities want to have vocational skill development training. Most of them want agriculture-based training. Many of them are not sure what skill they can learn and utilize for making some income. The detail is presented in the table below;

Type of training	Number of people willing to have skill development

<b>Chicken keeping</b>	180
<b>Goat keeping</b>	297
<b>Pig keeping</b>	82
<b>Vegetable farming</b>	75
<b>Managing small business (business skill)</b>	143
<b>Running a small grocery shop</b>	81
<b>Sewing/Tailoring</b>	20
<b>Beauty parlor</b>	10
<b>Computer training (MS office)</b>	15
<b>Bamboo tool making</b>	15
<b>Mobile repairing</b>	5
<b>Others (Not sure what works for them but want to have some skill development training)</b>	1,150

Few people mentioned cycle repairing, motorcycle repairing, house wiring, public speaking, hotel management doll making and electric working like repairing electric equipment e.g. refrigerator, fan etc. Detail assessment needs to be made of people who want to have skill development training.

## Marital Status, ownership of property and Social Security

### Marital Status

<b>Marital Status</b>	<b>Number</b>	<b>Percentage</b>
Married	3597	58
Never married	2342	38
Divorced	14	0
Single (widow)	240	4

### Ownership of property and bank account

Only 21% of persons with disabilities reported that they have some property in their ownership. This data correlates with the data of employment of persons with disabilities and indicates that people who have some earning opportunities also own some property. 48% of persons with disabilities reported having a bank account. Since government pays disability allowance in the bank account, therefore, persons with disabilities must have a bank account to receive disability allowance.

## Attitude and Behaviour of the Family/ Community and Participation in social life

The majority of persons with disabilities reported that the attitude and behavior of the family, community and their peers are good. Only very few people reported the attitude and behaviour to be bad.

<b>Attitude and behaviour</b>	<b>Family and community</b>	<b>Peers and friends</b>
<b>Very good</b>	940	647
<b>Good</b>	3358	2522
<b>Fair</b>	1858	2654
<b>Bad</b>	37	70

66.76% of persons with disabilities who are eligible for casting votes (age above 18) casted their vote in the last election but none of the candidates in the election were persons with disabilities in the district. However, participation in decision-making is very low. 38% of persons with disabilities reported that they never get an opportunity to participate in any family and community level decision making and the same number stated that they get such opportunities very rarely and only 22% of persons reported that they usually participate in decision making.

## Access to information services

The Survey found that persons with disabilities have no or very low information on the availability of health and rehab services. Only 208 (3.35%) persons with disabilities reported that they have some information on health and rehab services available to persons with disabilities. Similarly, 5.30% of people reported they receive services as provisioned by the government. Total 883 persons received rehab services out of which 824 people received services from private sectors.

## Participation in SHGs, DPOs and other social organisations

<b>Involvement</b>	<b>Yes</b>	<b>No</b>
<i>Member of any DPOs or SHGs at district or national level</i>	360	5,833
<i>Member of SHGs or DPOs at community</i>	483	5710
<i>Played active and leadership role in SHGs</i>	294	5,899
<i>Awareness on services and entitlement to persons with disabilities by the government of Nepal</i>	653	5,540
<i>Receive training on human rights, advocacy, or leadership</i>	150	6,043
<i>Do you file a complaint when you feel that your rights are violated</i>	2,078	4,115

## Conclusion and way forward

The baseline survey has revealed that the rehabilitation need for persons with disabilities is very high in the Nawalparasi district. The high rate of congenital disability signifies the need for prevention of disability working with mothers and early screening of disability is important. During the survey, it was noted that child marriage is common in the hilly area and accessible consumption of alcohol has caused problems like stroke and kidney failure. The findings of the baseline study have supported the need articulated in the proposal highlighting the need for health and rehabilitation, education, livelihood and social empowerment activities.

Despite the effort of making it a comprehensive survey and include ALL persons with disabilities we realised that the training to identify all types of disabilities as classified by the government of Nepal was difficult for them. This was a learning for that the training days should have been increased with some trial interviews before jumping to collect data. We made a criterion that a volunteer should have got a smart phone and should be familiar un using social medias but afterward It was also realised that the use of mobile application which was not familiar to volunteers. They made plenty of group work and worked in pairs to collect data using mobile application but in the field some of them find it difficult. Therefore, some people with disabilities are left out and KOPILA Nepal will update the data if new persons with disabilities are found and make sure people who are in need are not deprived of services.

The estimation made when designing the project and findings of the baseline survey are almost similar. Therefore, it is expected that the project, to a greater extent, will address the need of the people. The rampant poverty even among non-disabled families, high rate of mother and child malnutrition, non-availability of health and rehabilitation services within the government system, unexpected natural disaster and very low awareness on rights compounded with Covid-19 are some of the challenges KOPILA Nepal should face during the implementation. Furthermore, most of the devices like wheelchairs, hearing aids, white canes are all imported from India or China which is severely obstructed due to Covid-19 related restriction, referral centres, who provide specialised services, are also running in reduced capacity. Therefore, some of the project activities are delayed this year. Hopefully, the situation will improve in the year 2022.

KOPILA Nepal will make an annual review of the project with municipalities and related stakeholder in December 2021 which will provide feedback if any changes in the project plan is required in the year 2022 and ahead. We express our gratitude to DAHW and BMZ for supporting KOPILA Nepal financially and technically to undertake this project and we are sure the lessons learned will be beneficial to all parties involved in the project.