



Report

# Nepal's cash allowances for children with disabilities

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Cover photo: A young boy on a wheelchair plays table tennis with his friends in Nepal. © UNICEF Nepal

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# Acronyms

<b>CBR</b>	Community Based Rehabilitation
<b>CBS</b>	Central Bureau of Statistics
<b>CTEVT</b>	Council for Technical Education and Vocational Training
<b>DOCR</b>	Department of Civil Registration
<b>DPA</b>	Disabled People's Association
<b>DPO</b>	Disabled Persons' Organisation
<b>DSA</b>	Disabled Service Association
<b>ETCT</b>	Emergency Top-Up Cash Transfer
<b>GON</b>	Government of Nepal
<b>HEOC</b>	Health Emergency Operation Centre
<b>HRW</b>	Human Rights Watch
<b>IDI</b>	In-Depth Interview
<b>INGO</b>	International Non-Governmental Organisation
<b>KII</b>	Key Informant Interview
<b>MOFAGA</b>	Ministry of Federal Affairs and General Administration
<b>MOFALD</b>	Ministry of Federal Affairs and Local Development
<b>NEPTA</b>	Nepal Physiotherapy Association
<b>NGO</b>	Non-Governmental Organisation
<b>NIDA</b>	Nepal Indigenous Disabled Association
<b>NISER</b>	National Institute of Science Education and Research
<b>NLSS</b>	National Living Standards Survey
<b>NPC</b>	National Planning Commission
<b>ODI</b>	Overseas Development Institute
<b>Rs</b>	Nepalese Rupees
<b>SSA</b>	Social security allowance
<b>UN</b>	United Nations
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disabilities
<b>UNDP</b>	United Nations Development Programme
<b>UNICEF</b>	United Nations Children's Emergency Fund
<b>UNWFP</b>	United Nations World Food Programme
<b>VDC</b>	Village Development Committee
<b>WHO</b>	World Health Organisation

# Terminology

This report uses terminology related to disability as discussed by the study respondents in this research, and also reflects the language of disability currently used by the Government of Nepal.

The research for this study was carried out during the process of devolution, and our study respondents mostly refer to the old system (e.g. VDCs) and previous names of ministries (e.g. MoFALD) as well as the roles and responsibilities within the government pre-devolution. As such, this is how we report these findings.

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# Executive summary

This report presents new evidence on children with disabilities in Nepal. It examines children and their families' experiences of disability, and issues relating to accessing the disability allowance and its support to children with disabilities. The study also looks at the effects of the earthquakes in 2015 on children with disabilities and their access to the disability allowance.

Using a mixed-methods research approach, the study analyses existing household survey data on people with disabilities from across Nepal, collected in 2014 and 2015 (Eide et al., 2016), and collects new qualitative data from in-depth interviews and family case studies with children with disabilities and their families in Khokana, Bhaktapur and Patan, alongside key informant interviews (January 2018).

## Key findings

**Firstly, children with disabilities and their caregivers' encounter a wide range of experiences, emotions and challenges related to disability.** Children with disabilities and their caregivers reported that they felt more stigma or discrimination towards disability in rural areas. In urban areas, increased awareness and the opportunity for people with disabilities to mix more with their peers was associated with a feeling of less discrimination against them.

Both children with disabilities and their caregivers raised concerns for the psychosocial wellbeing of girls and boys with disabilities, often with distinct gender dimensions. A specific area of concern that caused anxiety and worry for many caregivers was what would happen to and who would care for their children with disabilities when parents died or were no longer able to care for them.

Children with disabilities' opportunities to access services are often restricted, despite policy provisions of specialised support. For example, illiteracy rates are high for children with disabilities (45% compared to 11% of children without disabilities), with many children with disabilities dropping out of non-specialised school, largely in rural areas, as a result of their disability. Moreover, disability also has significant economic impacts on the household, with direct impacts coming from expenditure on health and/or a caretaker or parent being less economically active as a result of needing to care for the child with disabilities.

**Secondly, there are high exclusion errors from the disability identity card, and therefore the financial disability allowance.** The quantitative data based on existing survey data (Eide et al., 2016), suggests that

83% of individuals with disabilities (both adults and children) do not hold any disability identity card (which enables an individual to be eligible for a disability allowance). Our estimates using existing data also suggest that between 30% to almost 60% of beneficiaries holding cards and eligible for the allowance are not receiving it (depending on the data sources used). The quantitative data shows that the factors associated with a higher probability of receiving a disability card (of any category) include (Eide et al., 2016):

- the nature of disability: a more severe disability, having a disability for a longer time, and having a physical disability
- individual factors: being male, of working age rather than a child or elderly, being literate
- household factors: living in a rural area, having a less diverse diet, living with a female household head
- information availability: being aware of health services.

The qualitative data shows that there are a number of reasons why households of children with disabilities do not apply for, or do not receive, the disability identity card. These include lack of knowledge of the card and allowance, how and where to apply for the disability card, lack of appropriate documentation and challenges during the assessment phase. Another challenge is that there is not automatic link between receiving the disability identity card and receiving the disability allowance; recipient names need to be separately registered with the VDC.

**Thirdly, the household survey data shows that children are more severely disabled than adults, and that the disability allowance is more important as a cash transfer for children than for other disabled age groups.** Children have, on average, significantly more severe disabilities and have disabilities in more health domains compared to adults with disabilities. As such, the data also shows that the share of children with disabilities holding a disability card and eligible to receive the disability allowance, is significantly higher than the share of adults with disabilities. Because children with disabilities receive fewer other social security benefits than adults with disabilities, for children with disabilities, the disability grant is more important as a cash transfer than for other age groups with disabilities.

**Fourthly, beyond the application processes, challenges in the receipt of the allowance were also reported.** A few respondents mentioned that they faced long queues at the bank or the VDC distribution point, or lacked information about when they would be able to collect the allowance and as such relied on other people to

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communicate this (particularly those receiving other social security allowances who tend to know when they are being paid).

**Fifthly, in relation to the effects of the earthquakes on the receiving the disability allowance, most respondents reported that they were not greatly affected.** Those who were affected, reported seeing the ground shaking, and some mentioned cracks in their homes. Parents reported that their children with disabilities were more scared and harder to manage than their other children without disabilities, and therefore their parents were more concerned and anxious about them.

Few respondents mentioned any problems with the distribution of the allowance after the earthquakes – besides delays, which were not seen as a key challenge for beneficiaries. According to key informant interviews there was also no negative effect on programme delivery, although there were challenges with programme coordination due to the high level of actors operating in disaster relief.

One of the reasons that the earthquakes did not seem to affect receipt of the disability allowance for beneficiaries could be that the disability allowance was not a priority for families affected badly by the earthquake. Indeed, it is reported that caretakers were more occupied with managing their day-to-day life in temporary shelters and concerned about protecting their disabled children from aftershocks.

**Sixthly, to strengthen the shock-responsiveness of the disability allowance, attention must be paid to both the demand and the supply side challenges.** When thinking about strengthening the shock-responsiveness of the social security allowance (SSA) system, our study findings and the recent evaluations of the Nepal's Emergency Cash Transfer Programme indicate that the most pressing issues for the disability allowance are around accessing the disability allowance (UNICEF, 2015; Mertsens et al., 2017) and that accessing it in the aftermath of the earthquakes was a low priority for households. These challenges, combined with the high exclusion rates from the disability card – and thus allowance – suggests that significant efforts must be made to overcome exclusionary barriers if the disability allowance is to be made more shock-responsive. This is also especially important as it applies to children with disabilities, given the relative importance of the disability allowance for such children when compared with adults who are more likely to also receive other social support.

## Policy implications

Based on the analysis of the study's findings, we provide the following key policy considerations for improving the accessibility and effects of the allowance, including in the context of future shocks.

### 1. Raise awareness and make communications clear and simple about the disability card and allowance.

This includes providing clear and easily accessible information about the eligibility criteria and the process for applying for both the card and the allowance. Consideration should be given to ensure that individuals with severe disabilities and their families are able to access this information.

### 2. Improve the disability assessment process.

This could include ensuring that committee members are knowledgeable about the assessment criteria, organising more assessment camps, and ensuring that people with disabilities can access the assessment committees in their own community and more frequently.

### 3. Simplify the procedure for receiving the disability allowance.

Consider automatically enrolling red and blue card holders to receive the allowance (e.g. taking all the necessary details at the time the card is given to the beneficiary).

### 4. Make procedures for applying in current place of residence.

Consideration should be given to enable people who are not living in their original home locality to apply for the card and allowance as well as to receive the allowance in their current place of residence.

### 5. Ensure that infrastructure and services are accessible to people with disabilities.

For example, ensuring that banks are accessible to the disabled (e.g. braille is made available in the current transaction system for those people with sight impairments, and ATMs and banks are accessible by ramp for those with physical impairments), and that continued support is provided to people with disabilities who are unable travel to the bank or ward to receive the allowance.

### 6. Coordinate and make use of complementary programmes and services.

Many people with disabilities and their families reported that their wellbeing is also affected by stress, anxiety and worry about disabled children and their future. Opportunities should be explored to coordinate and link with other service providers such as vocational training institutes, children's life-skill and livelihoods programmes to ensure a more integrated approach to addressing the challenges people with disabilities face.

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## **7. Support the capacity of local service providers in municipalities and rural municipalities, to deliver services for people with disabilities.**

This includes increasing the technical skills needed to assess disability for the disability card, and developing a grievance and redressal service for those who are denied a disability card or experience problems with the delivery of the disability allowance. This suggestion also means government ensuring that the policies designed to support individuals with disabilities are implemented (especially in rural areas)

to in turn increase access to services and programmes and ease the financial burden of costs associated with disability (e.g. healthcare, assistive devices, etc).

## **8. Invest in data collection and analysis.**

Investment is needed to improve data availability of people with disability, the disability card and the disability allowance. Currently, data is not digitised or disaggregated by age at the federal level. Better data would improve programme design and delivery, and inform future shock-responsive adaptations at federal, provincial and local levels.

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# 1 Introduction

Nepal's disability allowance, which started in 1996, is one of the five social security allowance (SSA) schemes run by the Nepalese government, and provides cash transfers to people with disabilities. It is part of the government's approach to promote the inclusion and welfare of people with disabilities by adopting a set of policy instruments that protect their rights and entitles them to a number of discounts and services, including social protection (Government of Nepal, 2004).– These include the Rights of Persons with Disabilities Act 2017 and the United Nations Convention on the Rights of Persons with Disabilities. To access specialised services, people with disabilities need to be in possession of a disability identity card, which categorises individuals according to the severity of their disability.

As of March 2017, 199,490 Nepali citizens held the 2016/17 disability identification card (Budhathoki, 2017). However, the incidence of disability is thought to be much higher than this: the latest census, which was conducted in 2011, reported that 1.94% of the population –513,321 people – was living with some form of disability, and the National Living Standards Survey report (NLSS), also conducted in 2011, estimated that 3.6% of the population were people with disabilities (CBS, 2011a; CBS, 2011b). These overall figures are also well below global estimates, which suggest that 15% of the population has some form of disability. It is widely recognised that current figures in Nepal considerably underestimate the actual prevalence of disability (WHO, 2010) – though this challenge is not specific to Nepal: globally, indicators of disability vary widely depending on different methodologies used.

The low number of people with disabilities who hold a disability identity card is problematic because eligibility for specialised services and targeted programmes is dependent on ownership of this card. For instance, only people holding a red or a blue disability identity card (denoting the severity of their disabilities as assessed by the disability card process) are eligible to receive the disability allowance. Persons with disabilities holding red cards receive an allowance of 2,000 Nepalese rupee (Rs) a month (\$19), while blue-card holders receive an allowance of Rs 600 (\$6) a month. Recent studies have shown that allowances (particularly the larger full allowances) positively contribute to the economic wellbeing and health of recipients (Roelen and Chettri, 2016). However, there are also high exclusion errors and barriers to accessing the disability allowance, and limited disaggregated data at the national level on the disability allowance, including data that relates specifically to children and young people and their households (ibid.).

Moreover, given Nepal's high vulnerability to shocks such as earthquakes, floods, landslides, drought etc. there is increasing interest in strengthening existing SSA

schemes to become more 'shock-responsive'. In 2015, two earthquakes struck Nepal on 25 April and 12 May causing substantial injury, new disabilities, and both economic and human losses. Research suggests that people with disabilities face specific risks and vulnerabilities in disasters. For example, people with disabilities may be unable to relocate easily to safer places during disasters such as floods and earthquakes (Peek and Stough, 2010). However, disaggregated information about children is not readily available, and this represents a key challenge in identifying their needs and providing the relevant assistance in times of emergencies.

In response to the 2015 earthquakes, the SSA system was scaled up to distribute 'top-up' allowances to beneficiaries, including beneficiaries of the disability allowance. This Emergency Top-Up Cash Transfer (ETCT) provided a one-off cash benefit of Rs 3,000 (approximately \$30) to help beneficiaries cope with the effects of the earthquakes. In total, 15,678 disability allowance beneficiaries living in the 19 districts most affected by the earthquakes were eligible for the ETCT (UNICEF, 2015). However, an impact evaluation of the programme revealed that people with disabilities faced challenges in accessing this ETCT– due primarily to the lack of available transportation to reach the pay points, or the loss of disability identity cards. As such, only 53% of people with disabilities collected their own transfer (compared to over 85% of widows and 84% of senior citizens) (Lord et al., 2016; UNICEF, 2015).

In this report, we present the findings of a research study that examines disability and the disability allowance scheme in Nepal. The study focused on children with disabilities, paying attention to their experiences, the experiences of their families, and their access to the disability allowance. The research also looked at the 'responsiveness' of the disability allowance system in the aftermath of the earthquakes in Nepal in 2015.

This paper is structured as follows. The next section presents the research methodology, including the data limitations. Section 3 provides an overview of the policy and programmes relevant for people with disabilities, including key aspects of the earthquake response in 2015. Sections 4 and 5 focus on the findings from the quantitative and qualitative data analysis: section 4 discusses the characteristics associated with households with disabled children as well as children's and their families' perceptions of living with disability across a wide range of issues; and section 5 discusses the accessibility of the disability allowance for children and their families, the barriers faced in obtaining disability cards and the allowance, as well as the effect of the 2015 earthquakes. Section 6 concludes with a summary of the key findings and presents a number of policy implications.

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# 2 Research methodology

This research study employs a mixed methods approach, combining: a desk review of relevant published and grey literature; a quantitative analysis of a dataset on individuals with disabilities across Nepal; and generated new primary research from qualitative methodology by interviewing children with disabilities and their caregivers' and family members, and key stakeholders at the national and local level.

## 2.1 Literature review

We conducted a literature review at the start of this project to provide relevant background information on: disability in Nepal, with a focus on children with disabilities; policies and programmes targeted at people with disabilities, including social protection measures and the disability allowance; and the effects of the earthquakes on people with disabilities and on the disability allowance. We used general search terms relating to these areas, and a snowballing technique to identify relevant published and grey literatures.

## 2.2 Quantitative methodology

The quantitative analysis employed the SINTEF Technology and Society dataset on individuals with disabilities across Nepal (Eide et al., 2016). This is the most recent dataset that focuses on individuals with disabilities in Nepal, and has a sufficient sample size to make inferences for our objectives. The sample is representative across all of Nepal.<sup>1</sup>

The dataset consists of interviews with 2,123 individuals with disabilities and 2,000 individuals without disabilities, selected using propensity score matching, and interviews with the household heads. 'Disability' is defined following the Washington Group on Disability Statistics.

The SINTEF data allows us to look at individual and household characteristics of individuals with disabilities. It does, however, have some limitations:

- The data was gathered during December 2014 and February 2015 – before the earthquakes in

2015. However, we still try to probe the shock-responsiveness of the disability allowance in a number of ways by looking at variation in prevalence of disability and the probability of holding a disability benefit or getting a disability benefit in a number of dimensions. First, we compare regions that were affected and those that were not affected by the earthquakes in 2015, to scope for any existing differences prior to the earthquakes. Second, we compare the areas that were or were not affected by the major flooding in August 2014, which took place before the data were gathered, to give an indication of responsiveness to a natural shock. Third, we use questions on housing quality, as individuals living in worse housing conditions are likely to be more negatively affected by earthquakes. Whilst the overall sample size is sufficient for our general objectives, the sample size is not large enough to look into detailed subsamples.

- For individuals with disabilities, and particularly for children with disabilities, answering questions during an interview may present challenges. As such, two-thirds of the interviews with children with disabilities were held with someone else present or answering on their behalf.<sup>2</sup>
- The question of whether individuals held a disability card was asked only a few weeks after the start of the data collection. Because of this, 35% of the sample were not asked this question. Assuming that the order in which the individuals were interviewed is random, this does not bias the results but only increases measurement error. However, there are indications that individuals with more severe disabilities are overrepresented among those that were not asked this question.<sup>3</sup>

## 2.3 Qualitative methodology

### 2.3.1 Development of research tools and training

We developed the research tools for this study in a participatory manner, led by ODI, with inputs from the United Nations Children's Emergency Fund (UNICEF)

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1 The study team had planned to use the World Bank 2016 Nepal Household Risk and Vulnerability Survey, but were unable to due to limited data on disability in earthquake-affected areas.

2 Note that the survey has data for disabled individuals aged 3-80. However, in the regressions, we use individuals aged 5-80 in order to have basic data on school enrolment and literacy.

3 Those who were not asked the question have significantly more severe disabilities (a mean activity limitation score of 9.3 vs. 8.7, and average number of disabilities of 2.0 vs. 1.7). This significant difference remains if we include the factors associated with prevalence of disability as control variables.

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team and the in-country research partners, the National Institute of Science Education and Research (NISER).

Prior to fieldwork, the study team spent a day examining the tools in detail, discussing and clarifying key concepts and terminology, and ensuring the logistical arrangements were in place. The tools were also tested and modified accordingly. The study team also took into account the highly sensitive nature of the enquiry when designing the tools, discussing the interview length, whether to use visual approaches, how and with whom informed consent should be taken, and ensuring the research team were prepared to face potentially difficult situations. The team decided that they would only conduct interviews with children of 12 years or above as this age group would be better able to respond to the questions asked, and that children with learning disabilities would not be interviewed (see also section below on study limitations).

### 2.3.2 Site selection

To explore differences in access to the disability allowance and experiences of living with disability, the team interviewed children with disabilities, and their caregivers and siblings in one rural and one urban site affected by the 2015 earthquakes. The sites chosen were near Kathmandu due to resource constraints. But although there are many such sites around Kathmandu, by searching according to geographical area, it proved difficult to find appropriate respondents necessary for the study – that is: children with disabilities, holding different coloured disability cards, receiving the disability allowance; children disabled by earthquakes (see also next section); and their elder siblings. As such, and after various consultations, the team identified locations with service centres for children with disability and which had been affected by the earthquakes, and then searched for relevant study respondents in these sites. Nonetheless, many of the respondents – if not most – were able to talk about the differences between rural and urban areas as most originated from a rural area where they had lived before coming to the service centres in Kathmandu valley. Hence rural and urban differences, where relevant, are brought out in the analysis through the experiences of the respondents.

The study locations and the sites from which respondents were recruited included:

1. A disabled service association (DSA) consisting of a children's hostel in Khokana of Lalitpur Sub-metropolitan city, which can be classified as a peri-urban area. The hostel is a private facility and runs primarily on donations. It is adjacent to a secondary school that has a resource class for children with disabilities and also has older children with disabilities integrated within the main school.

2. The Bhaktapur Community Based Rehabilitation (CBR) Organisation, which is in an urban area and consists of a day centre for children with disabilities, and a training and research centre, including a library.
3. The Patan Community Based Rehabilitation (CBR) Organisation, which is in an urban area and consists of a day centre for children with disabilities and a training centre.
4. The Nepal Disability Fund for people who became disabled due to the earthquakes.<sup>4</sup>

Snowball methods where we asked the respondent to point us to other possible respondents were used to find other respondents.<sup>5</sup>

### 2.3.3 Study respondents and sample size

The study gathered qualitative information from 40 individuals split equally between urban and rural areas. We interviewed:

- 14 children (aged between 12-18 years) with disabilities (8 female and 6 male) and 1 adult (24 years) man with disability. There was only one child who was newly disabled by the earthquake;
- 10 caregivers (5 mothers, 3 fathers and 2 brothers-in-law) were interviewed;
- 7 family case studies (consisting of 7 siblings – 3 sisters and 4 brothers and 7 parents 3 fathers and 4 mothers);
- 10 key informants including government and NGO representatives (see also Annex 1).

### 2.3.4 Analysis

With appropriate consent, all interviews were recorded, and then translated and transcribed. The study team jointly developed a coding structure, and all the interviews were coded and entered into MaxQda. Data from the coded segments was summarised according to agreed-upon themes in Microsoft Excel, and the analysis also explored issues emerging across different variables including site/location and gender. The analysis was then written up in the agreed report outline.

### 2.3.5 Study limitations

**Identifying children who were newly disabled as a result of the 2015 earthquakes.** One of the study's objectives was to examine whether the disability allowance system could respond to an increase in people with disabilities as a result of the earthquakes. Despite considerable effort by the team, they were unable to identify children who had been newly disabled as a result of the earthquakes. To reach such children, more time and funding would have been needed – for example, to travel to other earthquake-affected areas. In fact, key informants working on disability such as disabled persons'

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4 The central office is situated in the Social Welfare Office Kathmandu, and they work with local partners in the districts.

5 Further details of the programmes in these sites can be found in Chapter 3 and Annex 3.

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organisations (DPOs) throughout Nepal reported that they were not aware of any such children.

To get the perspective of someone who had been newly disabled by the earthquakes, the study team, with help from the National Disability Fund, identified adults. The numbers of such individuals were limited due to the fact that they did not live in Kathmandu and had not left any further contacts when they stopped receiving support. So only one such individual whom the team was able to track was interviewed.

**Identifying children with disabilities who were receiving the allowance.** While there are lists of those receiving the allowance by district, municipality and gender, and by level of disability allowance card they receive, this information is not disaggregated by age. It was only by going to the municipality and looking through the lists that the age of the individual could be ascertained. Even then, there were very few individuals below the study cut-off age of 18 years. The study team therefore identified children through the service centres. However, as all cards were kept by parents or caregivers (who also mostly access the allowance on behalf of their children) many disabled children did not know whether they had a card, which colour the card was or how much they were receiving.

It also proved difficult to find children receiving the disability allowance who could respond to the interview – that is, many such children had a learning disability. Interviews were limited to children with physical disability, who could speak to us and not with those with learning disabilities or those who used sign language for communication.

In an ideal scenario the study team would have wanted to talk to children as young as 10. However, it was agreed that interviewing from children around the age of 12 to 15 years, would allow for a more informed discussion – especially on the effects of the disability allowance on their lives. To obtain further insights, the study team asked questions about the respondents' experiences when they were younger. The team did interview some younger children (see age range in section 2.3.3), but often they – and even the older children – **were unable to say much about the disability allowance and how it has affected their lives.**

Caregivers were critical respondents in the study: they were often the ones receiving the disability allowance on behalf of a child and, if the child with disabilities was a red card holder or had an intellectual disability, responded on their behalf during interviews to the card verification

committee. The study team asked caregivers about the life of the child in their care, how the disability allowance has affected them, and the effects of the earthquakes, among other things. Similarly, while direct, first-hand perspectives were obtained from the blue card holders who were blind or who had other less severe disabilities, the study team was unable to obtain first-hand perspectives from the children who were severely disabled.

Despite much probing and triangulating with different study respondents, we did not find evidence of the impact of the earthquakes on the disability allowance. While there were delays in receiving the allowance, respondents had relatively little to say about the effect of earthquakes on the allowances. Also, given that the earthquakes happened three years from the date of the study, it is possible that memories of its impact have faded.

Given resource limitations, **the study was only conducted in the Kathmandu valley**, which was one of the areas most heavily impacted by the 2015 earthquake. Findings from the primary data collection are, therefore, particular to this area and the kinds of people residing there, many of whom are migrants from other areas of Nepal. Similarly, Kathmandu has a particular infrastructure and service environment which is not found in other parts of Nepal. Our findings are not therefore representative of the whole of Nepal.

Finally, we were not able to draw out in the quantitative or the qualitative data analysis significant differences according to caste and ethnicity. While caste and ethnicity determine many dimensions of life for a majority of people in Nepal including access to information, services, employment opportunities and community standing amongst other things, in this particular study, due largely to how respondents were sampled, caste and ethnicity did not appear to help explain the circumstances or any differences amongst study respondents. If the study were done elsewhere and if the sample size were larger and stratified purposively, for instance, by caste and/or ethnicity, differences may have emerged.

## 2.4 Ethics

Ethics approval was obtained from the internal ethics review committee at ODI and NISER. We obtained informed consent from all study respondents, with caregivers or guardians also given their consent for the research team to interview the children. Anonymity is maintained throughout this report: none of the respondents' real names are included.

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# 3 Disability in Nepal

## 3.1 Disability prevalence in Nepal

The inclusion of persons with disabilities has grown in importance in Nepal in recent years following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the enactment of the Rights of Persons with Disabilities Act 2017. Persons with disabilities have been defined as:

Those who have long-term physical, mental, intellectual or sensory impairments, functional impairment or which in interaction with various barriers may hinder their full and effective participation in social life on an equal basis with others (GoN, 2017).

According to the 2017 Act, disability in Nepal is classified into seven categories:

1. physical disability
2. disability related to vision
3. disability related to hearing
4. deaf-blind
5. disability related to voice and speech
6. mental disability
7. multiple disability

The 2011 National Living Standards Survey (NLSS) recorded that, of people with disabilities:<sup>6</sup>

- 29.2% are physically disabled
- 22.3% have visual disabilities
- 23.4% have hearing disabilities
- 2.4% have vision/hearing related disability
- 8.6% have speech related disability
- 6.8% have mentally health conditions
- 7.3% have multiple disabilities

(GoN, 2015)

However, and as in most developing nations, concrete data on the prevalence of disability in Nepal is hard to come by. Existing figures are disparate: while the latest census conducted in 2011 reported that 1.94% of the population (513,321 people) self-reported a disability, the NLSS conducted in the same year, estimated that 3.6% of the population were people with disabilities (CBS, 2011a; CBS, 2011b).

These figures are well below global estimates, which suggest that 15% of the population have some form of disability, and it is widely recognised that current figures in Nepal considerably underestimate the actual

prevalence of disability (WHO, 2010). Among other things, cultural barriers and sociocultural norms – including the belief that disabilities are a sign of sins in past lives – leads families to hide family members with disabilities, which may affect the actual data (HRW, 2011). Disaggregated data on disability among children is limited, and disabilities are not currently captured in birth registration forms.

The lack of standardised statistics on disability prevalence in Nepal leads to gaps in knowledge. This is particularly concerning given the strong links between disability and poverty, and that higher levels of disability are found in the lowest income quintile (GoN, 2012). Poverty, due to poor sanitation and lack of service access, can lead to disability: a situation analysis of disability, conducted in 2001, found that 30.3% of all disabilities were a result of disease or a lack of access to healthcare, which suggests that a third of disabilities in Nepal are preventable (NPC, 2001). Meanwhile disability can also trap people in poverty and lead to social exclusion by limiting access to employment opportunities and public services (HRW, 2011).

Moreover, there are also gender differences in reported disability rates, as well as gender and age differences in individuals' experiences of disability. For example, the national census data (2011) show a higher rate of disability among men (4.6%) than women (3%). Lord et al. (2016) suggest that this may reflect gender discrimination that reduces the survival chances of girls and women with disabilities, and under-identification of those disabilities among these groups.

## 3.2 Policy and programme environment for disability in Nepal

### 3.2.1 Overview of key policies

The Government of Nepal has taken several legislative and policy steps to address the challenges associated with disability (Box 1). The most recent of these is the Rights of Persons with Disabilities Act 2017, which:

- is guided by a rights-based approach
- is formulated in line with the UNCRPD and the disability-related provisions included in Nepal's constitution

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<sup>6</sup> Note that the For the SINTEF data the distribution slightly differs, with fewer reports of visual disability, and more people with multiple disabilities (Eide et al., 2016).

- features an amended from the earlier “Protection and Welfare of the Disabled Persons Act, (1982) classification of disability
- prohibits all kinds of discrimination based on disability, and provides actions and punishment against this
- provides for equal access for individuals with disabilities to education, health, employment, public physical infrastructure, transportation and information and communication services
- is developed in accordance with the federation system.

The policies and acts that have been put in place not only aim to ensure a rights-based and non-discriminatory environment for people with disabilities, but also include programmes and services that entitle people with disabilities to discounts, subsidies and social protection if they hold a disability card.<sup>7</sup> Such provisions include, for example: the disability allowance; free education for all children with disabilities; school quotas and scholarships for persons with disabilities; free healthcare and discounted medicines; financial support or free provision of assistive materials (such as prosthetics, hearing devices, wheelchairs, etc.); orphanages, rehabilitation centres and hospitals for individuals with disabilities; quotas in public and private employment; discounts on land and air transportation; and barrier-free new buildings of public importance.

### 3.2.2 The disability identification card

A person with disabilities of any age can apply to receive a disability identify card free of charge at the Women and Children Development Office of the concerned district, on the basis of assessment. The Nepal government has categorised the disability cards, and thereby the allowance, by severity of disability. There are four cards – *Ka*, *Kha*, *Ga* and *Gha* – coloured red, blue, yellow and white, which represent profound disability, severe disability, medium disability and minor disability, respectively.

The government’s draft bill “Disability Rights Bill 2017” (GoN, 2017) defines the four categories as follows:<sup>8</sup>

*Profound disability (Ka): Persons who are physically or mentally disabled, are unable to live their daily life without full support of others, fall under this category. These are people who are completely blind and mute; cannot move without the support of others or have severe intellectual disability. People falling under this category will get a red card with letter “Ka” written in bold letters.*

*Severe disability (Kha): Persons who require continuous support from others in their daily life’ but who are mobile, can communicate, are able to read and write; whose lower part*

#### Box 1 Key policies, acts and guidelines related to disability

1. The Rights of Persons with Disabilities Act 2017
2. The Constitution of Nepal 2015
3. Disabled Person Protection and Welfare Act 1982
4. Protection and Welfare of Disabled Persons, Rules 1994
5. National Policy and Plan of Action on Disability 2006
6. Ratification of United Nations Conventions on the Rights of Person with Disabilities, 2010
7. Education Act 1971
8. Education Act, New Amendment 2008
9. Education Regulation 2002
10. Civil Service Act 1992
11. Protection and Welfare Policy 1994
12. United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1992)
13. Education Act 2002
14. Special Education Policy 1996
15. Disability Allowance, 1996

*of the body isn’t totally functional due to polio or other reasons such as due to certain attack/ injury in backbone or brain haemorrhage and are supposed to use wheelchair; person not having their hands or legs and needing support to walk; totally blind; deaf; those who can live their own life but have problem in learning like the people with intellectual disability and the people who need support in their daily life due to their multi-disability get the disability card of group “Kha”. This type of card is blue in colour with letter “Kha” in bold letters.*

*Medium disability (Ga): Persons who can live their daily life with a supporting material; those whose body part below the knee (only) cannot function because of polio; those who can move freely but are physically disabled; those who are intellectually disabled and are very slow in learning; those who have a hunched back due to backbone problem; those who can hear only with the use of hearing device; those who are below the height of 3 feet; those with low-vision and use lens or magnifier for reading and those whose*

<sup>7</sup> See Annex 2 and sub-section below

<sup>8</sup> Note that the following paragraphs have been directly translated from the original document.

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*vocal cord is taken out after surgery are the ones who fall under group “Ga”. They are issued a yellow coloured card with a bold letter “Ga” highlighted in it.*

*Minor disability (Gha): People holding this card have minor physical problem but are still able to live their daily life without much difficulty. These are the ones whose hands or legs are shorter than normal; who have minor visibility problem; those who have at least a thumb or an index finger or the ones with missing toes; those who have minor hearing problem and those who have limited memory and are slow in learning. Those who fall under this group are issued a white card with bold letter “Gha” highlighted in it.*

### 3.2.3 Key sectoral programmes and services

Adults and children who hold a disability card are entitled to access numerous programmes and services, which can be grouped under four categories.

#### **Social assistance, subsidies, quotas and scholarships**

Red and blue disability card holders receive a direct cash transfer as part of the social security allowance scheme. A person with a red card receives an allowance of Rs 2,000 per month, while a blue card holder receives Rs 600 per month. Those individuals who were disabled as a result of the Maoist conflict are covered by special provision from the Ministry of Peace and Reconstruction, and receive Rs 6,000 per month (given to the person with disabilities) and Rs 6,500 per month for their caregiver.

Transportation and health policies provide for subsidies for people with disabilities, and there are also quotas in civil service employment (Annex 2). The government provides tax discounts to private firms that employ people with disabilities, and children with disabilities receive free education until high school and special scholarships after that. (It should be noted that health subsidies and school scholarships are only applicable to government-run hospitals and schools.)

#### **Assistive devices, physiotherapy and health services**

Assistive devices are sometimes provided free of charge to people with disabilities in Nepal include: hearing aids; glasses; crutches; and wheelchairs. In addition to this, physiotherapy sessions, speech therapy, lessons in sign language for both parents and children, as well as prosthetics and corrective surgery for children with disabilities are also available. These are provided through government institutions as well as INGOs and NGOs, and are funded by donors and government.

#### **Rehabilitation services**

Available rehabilitation services include a range of programmes such as community awareness, family training, and legal and livelihoods services for children with disabilities who have been abandoned and need legal support and money for enterprise. Rehabilitation services also include short-term accommodation, particularly for women and girls with disabilities. These services are usually provided by rehabilitation centres, and are funded by both government and non-government entities.

#### **Specialised education**

Specialised education includes integrated schooling, braille and other educational support for children with disabilities. While there are both integrated and special schools available for children with physical disabilities, those with learning disabilities have fewer options, most of which are based within rehabilitation centres.

Key programmes include:

Those provided by the government which can include the subsidizing or funding of services through various ministries. These include the support to disabled children through: the Ministry of Education; the CBRs through the Ministry of Children, Women and Senior Citizens (also supported by other I/NGOs); and<sup>9</sup> the disability allowance which goes through MOFALD.

Those run by Disabled People’s Associations or Organisations (DPAs / DPOs) which are essentially NGOs funded by external donors (INGOs, UN, private donations and /or supported by the government of Nepal) and running a range of different programmes from hostels, to rehabilitations centres, to providing awareness-raising activities, life-skills training, to carrying out advocacy related work. These DPAs fall under the umbrella of the National Federation of the Disabled Nepal. Many are networks and have branches / offices across the whole of Nepal.

The third category include the INGOs such as Humanity and Inclusion (previously Handicap International) who run a range of programmes including the provision of prosthetics and other special devices for disabled people.<sup>10</sup>

Special hospitals and health centres which provide services to disabled children including providing prosthetics and other assistive devices, physiotherapy services and rehabilitation services.<sup>11</sup> Annex 3 provides a snapshot of some of the service providers that were visited during the study, giving an overview of their objectives, programmes, target groups and their networks and funding sources.

Despite the policies and programmes in place, people with disabilities still face a number of challenges in

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9 And indirectly, supporting the Ministry of Federal Affairs and Local Development with funds then also allocated to supported disabled people through the wards, municipalities and ward citizen forums

10 Also through the social welfare council and the Nepali Disability Trust.

11 The funding sources are multiple ranging from the government to international donors and philanthropy organisation and individuals.

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accessing public services – these are discussed further in sections 4 and 5 below.

### 3.3 Earthquake response

The two earthquakes that struck Nepal on 25 April and 12 May 2015 caused substantial injury, economic and human losses, and had wide-ranging implications for people with disabilities. Research suggests that people with disabilities – and especially children – may be affected differently by natural-hazard related disasters. People with disability often lack the resources to evacuate threatened areas (Peek and Stough, 2010). However, it should be noted that as Lord et al. (2016) point out:

*Many Nepali persons with disabilities, however, maintain a great deal of agency despite a complex array of physical, mental and social limitations ... [People with disabilities] have different capabilities and ... these are often under-recognized.*

Natural-hazard related disasters not only present challenges to people who already have disabilities, but also lead people to sustain new injuries and impairments. In Nepal, the 2015 earthquakes killed 8,898 people and injured 23,000 (NEPTA, 2015). The prevalence of long-term disabilities among those injured during the earthquakes is still unknown, but preliminary estimates from the Health Emergency Operation Centre (HEOC) suggest that as many as 1,500 people –including between 200 and 300 individuals with spinal injuries – will require ongoing nursing and rehabilitation (ibid.). Research conducted in the Sindhupalchowk District found that 175 people had sustained disabilities in the earthquakes but did not have access to the disability card (Lord et al., 2016). However, disaggregated information about children is not available, and this represents a key challenge in identifying their needs and providing relevant assistance in emergencies.

In response to the 2015 earthquakes, the government of Nepal scaled up the disability allowance as part of the Emergency Cash Transfer Programme (ECTP), which they implemented in partnership with UNICEF.

The ECTP provided a one-off, top-up cash benefit of Rs 3,000 to existing social security allowance beneficiaries to help them cope with the earthquakes' effects. In total, 15,678 disability allowance beneficiaries lived in the 19 districts most affected by the earthquakes, and were eligible for the ECTP (UNICEF, 2015). However, an evaluation of the programme revealed that people with disabilities faced challenges in accessing the emergency cash transfer – particularly due to lack of available transportation to reach the pay-point (Merttens et al., 2017). As such, only 53% collected their own transfer (compared to more than 85% of widows and 84% of senior citizens) (UNICEF, 2015). On some occasions, the transfers were paid directly to people in their houses. One report also suggests that many people with disabilities lost their disability identity cards during the earthquakes and – for the reasons already outlined (section 3.2.4) – have been hesitant to apply for new ones (Lord et al., 2016).

Other earthquake relief efforts targeted specifically at people with disabilities were driven primarily by INGOs and civil society organisations such as Humanity and Inclusion. However, these organisations were not present in all earthquake-affected districts (Lord et al., 2016). People with disabilities found it harder than other groups to access information about the relief efforts (ibid). In turn, the few relief efforts that were focused on persons with disabilities were confined to easy-to-reach locations, further compounding the spatial exclusion. Having further to travel also presented a barrier to those with limited physical mobility – both in terms of reaching the distribution point but also in carrying the relief material home (Lord et al., 2016). The Nepal Indigenous Disabled Association found that in six districts affected by the earthquakes between 65% and 70% of people with disabilities did not receive relief (NIDA et al, 2018)

Several development partners also implemented public works programmes, including the United Nations Development Programme (UNDP) Safe Demolition and Debris Management Programme and the UN World Food Programme (UNWFP) Rural Access Programme. In both cases, however, limited availability of services that help in mobility of people with disability meant that they struggled to access these programmes (Eide et al., 2016).

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# 4 Experiences of disability

In this chapter we draw on both the quantitative and qualitative data analysis. The first section discusses the quantitative analysis which examines the characteristics of households with children with disabilities, including in shock-affected areas. Next, we explore the findings from the qualitative data collection and analysis, which looks at the effects of disability on various dimensions of life including psychosocial wellbeing, education, economic, voice and agency as well as future aspirations. We draw on perspectives of both children with disabilities and their caregivers, and include key informant interviews where relevant. We then present the kinds of coping strategies that children and their caregivers adopt, before exploring how they were affected by the 2015 earthquakes.

## 4.1 Characteristics of households with children with disabilities

### 4.1.1 The nature of disability

Analysis of the quantitative data analysis from the 2014 and 2015 SINTEF dataset (Eide et al., 2016) suggests that certain characteristics are associated with children with disabilities and their households.

First, children with disabilities have, on average, significantly more severe disabilities and are disabled in more health domains than adults with disabilities.<sup>12</sup> Approximately half of disabled individuals surveyed in the SINTEF study experienced a disability in one health domain, and almost a third in two domains. A larger share of children (15%) than adults (7%) had disabilities in four health domains or more, whereas fewer children (24%) than adults had a disability in two domains (33%). There may be a number of reasons for this, including that disability may increase with age (but be less severe), or that severely disabled individuals do not survive into adulthood.

Secondly, the quantitative data also shows that there are certain individual and household characteristics

that are associated with the prevalence of disability among children. To analyse this, we apply multivariate regression.<sup>13</sup> A higher number of household members (that is, larger household size) and a lower household socioeconomic status are positively associated with prevalence of disability among children. Individual factors of literacy and school attendance<sup>14</sup> are highly correlated with prevalence of disability; in other words, among children having a disability is associated with worse literacy and school attendance. In the SINTEF study, of the children with disabilities, 45% are illiterate, compared to 11% of the non-disabled control group; and for school attendance, 32% of the children with disabilities did not attend school compared to 3% of the control group.

Overall, prevalence of disability is higher in rural areas: 83% of the disabled children live in rural areas, compared to 75% of the non-disabled control group. However, this factor is no longer significantly associated with prevalence of disability in the multivariate regression design when indicators for household size, socioeconomic status and school attendance are included.

Thirdly, the survey analysis shows that the life experiences of people with disabilities reveal that people with disabilities are significantly less involved in social life – defined as making and maintaining friends, intimate relationships, and being included in household life and decision-making. This is even more the case for children with disabilities. Individuals with disabilities also experience stigma and prejudice, with a similar pattern of this being particularly true for children with disabilities. We explore these issues in more detail in the qualitative findings below. Interestingly, the quantitative analysis does not find strong gender differences – although the qualitative findings do suggest some exist.

Finally, although the survey for the dataset examined was conducted before the 2015 earthquakes, we also looked at whether more earthquake-prone regions, poorer housing or previous natural-hazard related

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12 Disabled children on average have more severe disabilities with an average mean activity limitation (MAL) score of 9.6 – statistically significantly higher compared to the average MAL of adults (8.8), and there is more variation in severity of disability (standard deviation of 3.3 vs. 2.2). Further tests point out that disabled individuals of working age on average have less severe disabilities, compared to both children and elderly (>65).

13 We use ordinary least squares (OLS) and logistic regression techniques, where we correct for the stratified sampling design.

14 These questions are only asked from age 5 onwards. For education, the questionnaire also contains questions on whether someone studied as far as planned, and years of education attainment. As these questions do not apply to younger children, we left them out of the analysis here.

disasters (i.e. floods) were significantly associated with the prevalence of disability. In this regard, we do not find any evidence that prevalence of disability was already higher in areas later affected by the earthquakes in 2015, nor in those areas that were affected by flooding in August 2014. Nor do we find any significant association between living in poorer quality housing (and therefore potentially being more vulnerable to the physical effects of earthquakes or floods) and having a disability.

## 4.2 Effects of disability on individuals and family

In this section, we present the findings from analysis of our primary qualitative data, collected from interviews with children with disabilities and their family members in Khokana, Bhaktapur and Patan, along with key informant interviews where relevant. These findings are very particular to the Kathmandu Valley and experiences of disability, access to services and attitudes among the community and service providers are likely to vary between a metropolitan area and a remote mountain village, for instance.

### 4.2.1 Psychosocial wellbeing

Both children with disabilities and their caregivers spoke about how disability had affected their broader psychosocial wellbeing, including the effect of this on relationships with others, how they were treated, and the kinds of stigma and discrimination they felt or were subjected to. Stigma and discrimination towards children with disabilities seemed to be felt more in rural areas – largely because there were fewer people with disabilities, awareness of their needs was limited and because appropriate and/or adapted services and infrastructure were not available. Meanwhile, in urban areas, because of increasing awareness and as people with disabilities interacted more with their peers the general feeling was that discrimination was less. In fact, most of our respondents with disabilities compared their lives back home in rural areas with how they were living now.

Both the children with disabilities and their caregivers raised concerns for the psychosocial wellbeing of disabled girls and boys. However, there is a sense that caregivers are more concerned about the safety of disabled girls given that, according to them, they are more vulnerable to abuse and violence than boys. Clearly, the extent of this is also dependent on the kind of disability the child has and the extent of protection and care the family can afford. Our study finds that this can also be contextualised within the prevailing social norms in Nepal whereby the protection of girls, alongside safeguarding their honour, guides many aspects of life and is critical to maintaining the wider family's reputation. For boys, social norms around attributes and behaviour are more focused on the idea of providing for

their families and households. These issues are explored through the narratives of study respondents below.

### Children with disabilities' perspectives

One girl with disabilities – a defect in one of her feet since birth – spoke about how, when she had been living in her rural village, she felt different from other children and was sad because she could not mix with them:

*I felt different than them (other children). They used to run and walk fast but I couldn't. I wished I was like them.*

*IDI, 12-year-old-girl with physical disabilities, Khokana*

While she did not feel that her peers or others discriminated against her (possibly because her disability was minor), other respondents spoke of feeling humiliated and being picked on ('I felt like I was made fun of' – IDI, 15-year-old boy who is blind, Bhaktapur) and punished by teachers in rural areas when they were unable to accomplish their studies or learn at the same pace as their peers. This caused them to want to withdraw from school but they were forced by their parents to continue.

One boy noted that, when living in the village, his non-disabled peers and his extended family treated him badly:

*The children in my village used to make fun of me calling me a blind person. And even at home, my maternal uncle's family did not treat me very well ... I felt bad. I had problem in my eye and even my mother was not well.*

*IDI, 15-year-old boy who is blind, Bhaktapur*

But once this same boy moved to an urban area and became aware of other children with disabilities, he no longer felt this humiliation. This was also the experience of another boy from Bhaktapur, who noted that once they grew up and realised they were not alone and that there are other children with disabilities, they stopped feeling bad about themselves "Yes. I feel good now [about myself]" (IDI, 13-year-old boy who is blind, Bhaktapur).

Feelings of stigmatisation in rural areas were also evidenced in the fact that, during school holidays, children with disabilities would rather stay at the school than return to the villages in which they may have had bad experiences. This implies that their current residence or school provides them with a more welcoming and nurturing environment.

*Well, I don't have any friends there [in the village] and nobody will be around. So all I can do is watch TV and listen to music on my phone. That's it ... There are many toys here [in the school in*

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*urban area]. So I can play and wander around with my friends here.*

*IDI, 15-year-old boy who is blind, Bhaktapur*

Staying in school during holidays also was a result of difficulties in travelling back to home villages where there is no transportation. One boy, for example, was living in a hostel and had not returned to his home in Humla for eight years because the lack of regular transportation meant he would have to walk for days – something he cannot do.

Another factor that made children – and largely older boys – with disabilities feel sad and anxious, was their awareness that as they grow older they will most likely not be able to earn an income like other boys or young men of their age nor be able to take on familial responsibilities. This was also mentioned by caregivers. Social norms are likely drivers of these concerns.

*“He worries whether he can earn money like normal people and he worries about his parents and wonders if they will ever be happy. All his friends that are of this age have gone to Gulf countries and have returned back earning some money and their economic status has improved. He hears these things and feels sad and thinks that if he was not blind then he too would have gone abroad to earn money. In fact, he once asked me to help him to go abroad to earn money but I didn’t motivate him and instead told him to first pass his class 10 exams.”*

*IDI, Brother-in-law of partially sighted boy, Khokana*

### Caregivers’ perspectives

Like the children with disabilities who we interviewed, caregivers also noted that discrimination towards these children and indeed themselves was higher in rural areas than in urban. According to the respondents, there were two possible reasons for this. First, that, according to these respondents in urban areas people are less concerned with what other people do and there was a sense that they were not so ‘nosy’ as those in rural areas. Second, caregivers also mentioned – as did the children – that it was often family members in rural areas who discriminated against them. As relatives often do not live nearby in urban areas, with people often living in smaller, more nuclear-style households, this also resulted in a decline in discrimination:

*I always used to cry, every day. Because of my daughter’s condition others dominated her. Even at home the problem was the same. There are many brothers and they have many children, my mother-in-law and father-in-law used to treat her differently than their other grandchildren.*

*IDI, Mother of girl who is deaf and non-verbal, Chakupat*

Many respondents highlighted the differences between rural and urban areas, and one mother noted that both she and her daughter are much happier having moved to an urban area where her daughter is with other children like her.

*In Kathmandu, as you know, people don’t care about their neighbours so much. If there were relatives living in my neighbourhood then maybe they could have discriminated but that is not the case.*

*IDI, Brother in law of partially sighted boy, Khokana*

*In the village, people say that the parents have committed sin so the child is born that way ... I hear that a lot.*

*IDI, Father of boy with no hands or limbs, Kamalpokhari*

*She used to go to play with her friends, she could not understand what they said and because of this they used to exclude her from the group. And she used to weep coming home saying, ‘They didn’t let me play with them’. There was the communication gap between them. Now she has the similar friend who can understand her, who plays with her. There was lots of such a problem in the village ... a big tension for me was a maltreatment of friends to her.*

*IDI, Mother of girl who is deaf and non-verbal, Chakupat*

Within urban areas, there were some mixed views about the degree to which children with disabilities were discriminated against by the wider community. Some parents and caregivers said that not all people in the community were kind towards children with disabilities, while others reported receiving support from their neighbours:

*“Neighbours aren’t afraid as they know her and they rather bring her home as she might be roaming in the park. But strangers who come to park get scared. Sometimes she even tries to beat them so they run away.”*

*IDI, Mother of girl with learning difficulties, Gwarko*

Caregivers also said they were stressed and anxious about the wellbeing of the children they were caring for. On the one hand, respondents expressed concern that their child may be violent towards others, as one mother explains:

*“She is not like normal children she doesn’t understand things and so I am worried that she may*

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*be beat someone up, earlier she used to spit at other children but now she has stopped doing that.”*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

On the other hand, caregivers were also anxious about the physical safety of the children themselves – and particularly girls – feeling they needed to constantly watch and protect them, including locking them inside the home:

*I lock the home to keep her inside, I have to use a padlock. She hasn't been able to open it otherwise she can open latches which she couldn't open previously ... She takes a long time in toilet. Sometimes my husband says to search for her as she is quiet in toilet. Even though we know she can't get out we have that fear that she might someday and we wouldn't be able to search for her in dark.*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

There was also fear on the part of caregivers that people may take advantage of and abuse disabled children, and particularly girls:

*As she is mentally ill and almost adult, I constantly fear that some males might try to abuse her in absence of family.*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

Key informants also spoke about sexual harassment and violence, including rape, towards disabled girls. According to one respondent, 25 rape cases had been reported to the disabled women's association in the last two years. Domestic violence also exists but, according to this respondent, it was not reported due to issues of privacy and family honour:

*We heard many cases where parents remove their intellectually disabled daughters' uterus so there would not be complication in future due to rape case.*

*KII 1*

This key informant confirmed that their organisations are raising awareness on this issue.

According to one of our respondent's younger brothers, his sister had been subjected to sexual violence and was raped by an elderly neighbour. He explained that their uncle and a representative from the Community Based Rehabilitation (CBR) centre helped her to seek justice, and after the girl's mother filed a police report, the perpetrator was arrested and jailed.

*An old man from the neighbourhood gave her sweets to eat and raped her. Our uncle and the Miss from the CBR took him to the police station with my mother and now he is in jail.*

*IDI, Brother of girl with learning difficulties,  
Gwarko*

One concern voiced by many caregivers was what would happen to, and who would care for, their children with disabilities when they died or were no longer able to care for them. In the case of one child with learning difficulties, his parents were hoping that their child would die before them:

*He is my son so I should not say this. But I wish he would die before us. What to do? Our constant worry is who will take care of him after we die? He will have a very hard time after we die.*

*IDI, Father of boy with multiple disabilities,  
Patan*

One mother also noted a gender dimension, saying that if she dies, her husband would not be able to care for her daughter:

*Since she is a girl, after my death her father cannot take very good care of her. I constantly think about this and I fear the future.*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

Caregivers also said that their child with disabilities was also a source of tension between spouses – largely around who should care for the child and how they should be cared for. Spousal disagreements in turn fuelled the child's psychosocial distress:

*Yes, sometimes, I beat her when she doesn't obey me. Then he [my spouse] doesn't feel good that I beat her so he scolds me. Then we quarrel about the situation. I say that he should be able to take care of his daughter as well. What will he do if I die? During our quarrel our daughter gets irritated and angry with her father and screams.*

*IDI, Mother of girl with learning difficulties,  
Patan*

Spouses also argued about the need to protect their daughters in particular – which stems from social norms that limit girls' mobility. One father was initially reluctant to send his daughter to the disabled centre:

*At first when we left her here he was angry with me and he did not speak. He did not have food at home. Later he came to understand. Our daughter*

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*began to write her name and after seeing this he became happy thinking it is kind of good.*

*IDI, Mother of girl who is deaf and non-verbal,  
Chakupat*

Key informants also mentioned that husbands sometimes abandoned mothers due to a child having disabilities, which affected the wellbeing of both the mother and the child.

#### 4.2.2 Access to education

According to study respondents, few educational facilities for children with disabilities exist in Nepal in general, and are more or less absent in rural areas (see also Chapter 3). Various key informants also noted that while scholarships are available for children with disabilities, the amount was insufficient and some families were unaware of their existence. Teachers often also did not know about them and were therefore unable to pass on information to children or caregivers. In rural areas, none of the children with disabilities interviewed attended specialised schools in their district of origin; respondents reported that either children did not or could not go to school or went to specialised centres which are different to specialist schools.

One boy wanted to leave school because he felt that he was wasting his parents money; according to him, what chance did he have when even educated, people without disabilities were unable to find employment:

*He says there is no point of studying further as he is 100% sure that he won't get any job because even able body people are not able to get a job here. So why would he get a job, the amount of education he has had is enough for him to start his own business.*

*IDI, Brother-in-law of partially sighted boy,  
Khokana*

Despite availability of specialised schools and hostel services, there are **enrolment and financial challenges**. Although the school provided free education for children with disabilities who lived in the Disabled Service Associations, they had to pay for other services such as the hostel and stationery. Moreover, some respondents spoke about having to pay fees while others who had attended or whose children had attended the same institution did not. Information about regular tuition and service fee structures differed among respondents: admission fees ranged from Rs 400–2,000 (\$4–\$20) while regular fees ranged from Rs 400–1000 (\$4–\$10). These differences appear to relate to the economic circumstances, with discounts given to children whose parents cannot afford to pay the full fees.

Caregivers also spoke about the discrimination they faced when trying to enrol a child with disabilities into school:

*I think he does face discrimination because when we tried to admit him to a school, that school refused to take him.*

*IDI, Mother of boy with learning difficulties,  
Lagankhel*

This was also mentioned by a key informant who noted that, as parents would usually need to spend more money to send a child with disabilities to school, they give lesser priority to the disabled child if resources are scarce. As such parents with economic problems often do not see education as a viable option for a child with disabilities. They feel that the child cannot be a breadwinner or have future employment opportunities. The same key informant also noted that this is particularly true for girls as parents know that it will be hard to 'marry off' a disabled girl, and so do not want to invest in her education. With boys, on the other hand, they still hope that he will be able to earn something for them in future:

*Since parents think that their disabled daughter won't get married in future, so they don't think sending them to school is worthwhile. For their sons, they are more open and they feel that their son will look after them in future. So they send them to school even if they are disabled.*

*KII 3*

Enrolment in a specialised school also requires certain documentation, which is not always easily or quickly obtained:

*After that incident [when he lost his eyesight] I took 1-2 years gap ... We (also) spent a whole year in the process of making documents to get me enrolled in such a [specialised] school.*

*IDI, 17-year-old boy who is partially sighted,  
Bhaktapur*

**Activities and teaching modality** varied depending on the severity of disability. Rather than focusing on academic subjects, specialist centres focused on doing craft or dance activities, and taught children how to support themselves in their day-to-day life. Such an approach is relevant to children with medium to severe disabilities and to those with learning difficulties.

For children who are blind or deaf, there is more scope to focus on academic subjects and with specialised schools and resource classes which are special classes for children who are blind and deaf this is possible, as was noted by some of our study respondents who were blind and attending an integrated school.

However, there are **barriers to learning**. Children continue to face difficulties and tend not to do as well as their peers without disabilities: those who are blind and use braille said that there are not enough braille books to cover all subjects, while children who are partially

sighted and do not use braille said they are unable to see the classroom whiteboard. Even if children are provided with a specialised teacher or writing assistant, they still do not do as well as their peers.

The pattern emerging from the interviews was that many disabled children had dropped out of non-specialised schools, largely in rural areas, as a result of their disability and the fact that schools were ill-equipped to accommodate them. Among the study respondents who were recruited for this study in or through specialised centres, many were fortunate enough to now go to specialised schools, or schools with resource classes. Despite plans by the Ministry of Education to scale up these schools they are still mostly located in and around Kathmandu.

Reflecting on the reasons why they or others may have previously dropped out of school, respondents noted that in rural areas (and to some extent urban areas), children with disabilities find it difficult to study, to concentrate, to follow the class, and as they get further and further behind, they cannot cope. As mentioned in section 4.2.1, teasing by fellow students and punishment from teachers for poor performance is another important driver of school drop-out, as is the frustration children may feel for being unable to take part in play-related activities.

Corporal punishment is still widespread in schools in Nepal. As many teachers are unaware that students with learning difficulties need specialised assistance and cannot learn at the same pace as other students – even if they try – these children are more vulnerable to punishment:

*My son did not say this to me. But his friends told me that he gets beating from teachers and they keep him naked as punishment for not being able to learn things. When I heard this, I could not cope. So I took him out of that school.*

*IDI, mother of boy with learning difficulties,  
Lagankhel*

According to some study respondents, many children who are blind and without supportive infrastructure and training (i.e. braille) never even went to school. For others, the lack of disability-friendly infrastructure meant it was difficult for children to participate in daily classes, and resulted in them not wanting to go to school:

*I could only ride my wheelchair up to half way and my father used to carry me and take me to class. Even after I got prosthetic leg, I didn't use to want to go to school because of the road condition.*

*IDI, 17 yrs old girl with double-leg amputation,  
Nepaltar*

Fear of accidents happening on the way to school made some parents choose not to send their children with disabilities to school – especially if the school was far

from home or it was during monsoon season, when the probability of accidents in some areas is heightened. This affects the regularity with which children with disabilities attend school – another reason for them falling behind in their classes and compounding the desire to drop-out. One caregiver was able to afford a private tutor for his son – a double-leg amputee; his son now boards at a disabled hostel.

Another significant pattern emerging from the study was that students often dropped out of school for a number of years and, if they were fortunate enough to return, were then significantly older than their peers without disabilities. For those who completed school – mostly children who were blind or had minor disabilities such as speech impairments or had difficulty hearing – they did so much later than their peers. This again caused students not to thrive, or to drop out altogether.

Key informants also noted that lack of disabled friendly infrastructure, facilities and teaching methods in school has resulted in disabled children dropping out of school, also noting that this effects disabled girls more than boys:

*Girls have to skip school when they have periods as they are unaware of sanitary pads and schools don't have proper facilities. So they are ashamed to go to school. When they skip few days it directly affects their studies and finally they drop out of school.*

KII 3

### 4.2.3 Economic impacts of disability

Parents, siblings and children with disabilities themselves are all aware of the additional costs that having a child with disabilities within the household brings. The economic impacts are both direct and indirect. Treatment – including the regular medication that some children need – along with costs related to specialised care and assistive devices, all have a direct economic impact.

But apart from the disability allowance and the Emergency Top-Up Cash Transfer, the government of Nepal has not provided any other financial assistance for basic household support or supplementary income for people with disabilities. Some families have taken out private insurance for their children while others have savings for them. Donations and pocket money given to children by visitors at the Khokhana hostel was also mentioned, but this is sporadic.

Regarding subsidies in treatment, respondents also said that, while they do not have to pay for check-up fees at government hospitals, they are required to pay for medicines at private clinics. They do receive a discounted rate, but have to provide their disability card. Some respondents who used health services also mentioned that they have experienced discrimination at private clinics, which makes them reluctant to show their disability card when buying medicine:

*Well the response from those at the medical store becomes very negative when they see the disability card, they start catering to other customers and keep you waiting for a long time or they will say that they do not have the medicine that I want. So I had done this once and seeing their reaction I felt like I was begging for money so I paid them the full amount and since then I have stopped using the card in such a way.*

*IDI Father of boy with learning difficulties,  
Bhaktapur*

Respondents also spoke about visiting special centres for physiotherapy and rehabilitation. Local NGOs such as CBR Bhaktapur run trainings for caregivers on how to look after and communicate with children with disabilities. The CBRs received funding from the government or INGOs (e.g. UNICEF) to do this work, and as such these trainings are free to those attending. The sessions are led by trained social mobilisers who also conduct household visits for families with children with disabilities.

Parents of children who are deaf or blind seemed to have spent considerable amounts of money and had decided to forgo treatment when it was not economically viable – for instance, taking a child to India for surgery or buying expensive hearing devices abroad as they were not available in Nepal.

*But the treatment in Nepal is not possible and treatment in India costs a lot of money. They said it would cost more than two million. Then we said to ourselves, ‘We can’t pay that much. So we cannot afford to take our child to India for treatment. If it was in Nepal, we could have tried but taking her out of Nepal is beyond our financial capacity.’ So we stopped taking her to the hospital in Nepal as well.*

*IDI Mother of girl who is deaf and non-verbal,  
Chakupat*

Regarding free assistive devices as mentioned in section 3.2.3, some respondents mentioned that certain assistive devices were provided free of charge by hospitals (such as by the Hospital and Rehabilitation Centre for Disabled Children in Banepa). However, there was no evidence from our study respondents that disabled children in rural areas received assistive devices, which were commonly available in urban areas.

According to several parents, assistive devices for individuals who are deaf seem the hardest to afford:

*[A group of doctors who came to village] told me that my son will hear if he puts on earphone which costs Rs 50,000 [\$486]. We bought him an earphone of Rs 12,000 (\$116.76) but it did not help. He could not hear anything. He didn’t want to use it and started throwing it around. We did*

*not force him to use it. At that time he was just three years old. So we thought we will make him use earphones when he gets a little older.*

*IDI Mother of boy who is deaf and non-verbal,  
Khokana*

For those with physical impairments, hospitals provide wheelchairs, prosthetics and crutches for free. Until recently, the Nepal Disability Fund in Kathmandu (run by the Social Welfare Council) also provided free devices and device maintenance for earthquake-affected people. However, this stopped a few months prior to our fieldwork. Others, who are partially sighted, bought magnifying glasses themselves (\$12).

Those with learning difficulties do not seem to have been referred to hospitals outside Nepal for treatment. In such cases, parents seemed to have spent less on initial treatment. However, some interviews reveal that parents of children with multiple disabilities who are in some cases also blind, spend more money because they need regular medication:

*Q: Does she have to take a lot of medicine?*

*A: Yes.*

*Q: And how much gets spent on medicine in a month?*

*A: I never buy the medicine so I don’t know exactly but I think normally it’s around Rs 1,000–1,500 (\$10–\$15)*

*IDI Brother of girl who is deaf and non-verbal,  
Chakupat*

While those with disability identity cards receive discounts on medicines, those without the cards have to pay the full amount:

*She [a child with multiple disabilities, epilepsy, learning and speech difficulties] needs to take a lot of medicine. So whenever we go to buy the medicine they ask us if we have the card but she doesn’t have the card so we don’t receive any discount on the medicine bills. If we had the card we could buy the medicine at a discounted rate.*

*IDI, Mother of girl with epilepsy, learning and speech difficulties, Bhaktapur*

Respondents’ views about payment for special centres and hostels were mixed: while said they had to pay monthly fees and additional costs, others attending the same centre said that they only paid for food and lodging. Some said that they did not pay at all. This variation in costs could be explained by the fact that the centre most probably exempts from charges those

who are on a lower income. In some cases, the hostel for children with disabilities takes the monthly allowances directly from their social security allowance and does not charge other additional sum:

*I don't know [how much I pay or whether it is monthly]. They take the [SSA] allowance [for disability] that I get from the government.*

*IDI, 15-year-old boy who is partially sighted, Bhaktapur*

The other major economic impact on households with children with disabilities is the loss of a parent or guardian's job or economic activity as they take on the role of caregiver:

*I left my job for two years. Previously my mother helped me to bring my child to the CBR and take her back since I had to be in the office and my duty shift changed frequently from between 7 a.m. and 10 a.m., to 10 a.m. to 5 p.m. But later my daughter disobeyed her and even lay on the road and didn't move. When I had office in Bijuli Bazaar I used to make an excuse and come to take her home during her period. But since it wasn't possible so I left my job for 2 years.*

*IDI, Mother of girl with learning difficulties, Patan*

One father reported having to sell his business to take care of his son:

*Yes, see I was the owner of brick kilns that was running successfully and had no problem with money. However, after my son was born I had to spend a lot of money and time on his treatment so I couldn't give time for my business and so had to close it down, I couldn't work in joint business with my friends or give enough time to anything because of my son's condition.*

*IDI, Father of boy with physical disabilities, Baneshwor*

#### 4.2.4 Voice and agency

Our findings show that disabled children played a limited role at most (if any role at all) in household decision-making, and this was the case for all children with disabilities – whether they are boys or girls, older or younger, and for all kinds of disabilities.

*Q: So now you are 16 years old. Does your mother ask you for any suggestions?*

*A: No.*

*IDI, 16-year-old boy with physical disabilities, Khokana*

For children with disabilities who live in specialised schools or hostels, their limited involvement in household decision-making might be because they are further from home and not part of day-to-day household activities. Boys and girls interviewed both said that their parents told them to study, do well and become a 'great person' rather than asking for their opinion on household matters or asking them to look after them in old age. There was only one case in which a child with disabilities was given greater autonomy and decision-making power. In this instance, the child with disability lives with a younger (non-disabled) sibling, away from their parents. The parents have opened a bank account in the name of the elder sibling, who has disabilities, and this child manages their own expenditure and that of their younger sibling.

Similarly, the schools that children with disabilities attended were chosen by parents, and we found no evidence of children being asked their opinion in this decision-making. In terms of activities in the home, while children who were blind or deaf helped with domestic chores (according to both the children and their caregivers), this is not the case for children with other forms of disability. There were some instances of siblings who both had disabilities helping each other with such activities:

*Q: Do you have to take care of [your brother, who is also blind] or help him in school?*

*A: I take him to class, wash his clothes, help him in homework and in studies. But he's more talented than me.*

*IDI, 17-year-old girl who is blind, Khokana*

In some cases, mothers of children with disabilities didn't want their child to do chores:

*She just tries to [wash clothes] for fun, copying me, but she actually doesn't have sense. Teachers tell me to teach her [to wash clothes] but I feel terrible to make her do such things. I will do everything for her till I die.*

*IDI, Mother of girl with learning difficulties, Gwarko*

In terms of self-care, while children who were blind or deaf were able to take basic care of themselves – changing their own clothes, eating, using the toilet and bathing – those children with learning difficulties or multiple disabilities largely depended on their parents or caregivers:

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*I have to help her in everything other than changing her trousers. Even that sometimes she wears it opposite. I have to help her also with changing sanitary pads.*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

The interviews also revealed that support for children with disabilities was gendered – especially as the children became older. Typically, fathers helped sons as they grow older while mothers continued to help girls as they became adolescents. Older siblings also contributed to this care work:

*Respondent: I feed [my sister, who has disabilities] and I help her put on her clothes.*

*Interviewer: Do you take her around?*

*Respondent: Yes.*

*IDI, Sister of girl who is deaf and non-verbal,  
Chakupat*

Even if the child with disabilities is able to care for themselves inside the home, caregivers do not allow them to go outside alone for fear that they might get lost, be abused or injure themselves. As such the mobility of children with disabilities – both boys and girls – is severely limited. When they do go out, they are accompanied – at home, mostly by parents or older siblings. Children in schools and hostels are also not allowed to leave the premises without supervision.

*He doesn't need any special care. We don't let him go outside the house alone and if he has to go, there is always someone accompanying him and helping. However, inside the house he doesn't require any assistance to move around.*

*IDI, Brother-in-law of boy who is partially sighted, Khokana*

*Yes. Even the principal tells us not to go outside without any reason. He tells us to ask the people who work here to run errands for us instead of us going outside ourselves.*

*IDI, 15-year-old boy who is partially sighted,  
Bhaktapur*

Caregivers interviewed said that their biggest challenge in looking after children with learning disabilities was to keep the children from running away where, again, there is the fear that they might be abused or injure themselves. For this reason, some lock their children inside:

*She always wants to go outside towards the park. She throws stone at the vehicle and sometimes*

*she even blocks their path. Thus, I keep her locked at home.*

*IDI, Mother of girl with learning difficulties girl,  
Gwarko*

Children with disabilities were also, according to caregivers, sometimes felt that they might be a burden to others, something that became more acute as they get older. One caregiver, who has been looking after his wife's brother during school holidays for four years as he is unable to travel home, said the boy was sensitive and tried not to be a burden:

*He never lets us know if he is facing any difficulties or not. He is very considerate person and he knows his surrounding well and behaves accordingly. For example, in the morning I bring him tea and I ask him to take it and he has a very good hearing skills and he figures where I am and grabs the glass. He tries his best not to let people know he is blind. So, he pays of lot attention to his every action. However, he can only see around 9% so still struggles to see small things.*

*IDI Brother-in-law of boy who is partially sighted, Khokana*

Caregivers experience that one major difference between their non-disabled children and their children with disabilities was around the levels of assistance that they need – which also clearly varies according to their particular disability. Both mothers and fathers said that their child with disabilities needs more care and looking after, and cannot be left alone in the home unlike their siblings. Parents also noted differences in behaviour: their children with disabilities got more easily frustrated and angry, and tended to cry or throw tantrums much more than their siblings who were not disabled. When outside the home, however, parents noted that their children with disabilities tended to remain silent, and be ignored and discriminated against, compared with their siblings who would ask for things.

*He does not know how to speak. He just remains silent and nobody cares for him. Those who can speak ask for things they need and they are given, but he does not ask anything and does not get what he wants.*

*IDI, Mother of boy who is deaf and non-verbal,  
Khokana*

#### 4.2.5 Future aspirations

Many caregivers expressed **anxiety about the future** of their child with disabilities, worrying particularly about who would care for them when they are not around.

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*We have to keep looking after her. She is still small. She has one elder brother who might look after her in future but we don't know how her sister in law will be. So we worry about her. If she can go to toilet and bath herself then it will be fine. She is studying so it would be great if she can read and write her name.*

*IDI, Mother of girl who has epilepsy, Chakupat*

For those whose children are deaf and blind, parents and caregivers are more hopeful about their future – especially when they are accessing specialised services such as schools, hostels or community-based rehabilitation centres.

*Yes and [his parents] are convinced that given where their son is now [in a hostel and attending a specialised school] they feel that he is no less than any normal boy. I also tell them that if he able to pass class 10 exams then he will be able to get at least a job and I will try my best to make sure that happens. I have told them that lots of foreigners visit that place and they could help him to go abroad where he can earn more money.*

*IDI, Brother-in-law of boy who is partially sighted, Khokana*

These caregivers were also hopeful that their children might secure a job under the government-mandated 5% reservation for people with disabilities. Others thought that their children could make a career in music, as this was a subject in which they were doing well at school.

Children themselves seemed to be more optimistic than their caregivers about their careers. Those attending specialised schools were positive about the future. The research did not uncover differences between the girls' and boys' aspirations, but there were more variations according to disability severity. Children with moderate disabilities aspired to start businesses of their own, to be doctors or engineers, or to become a braille teacher to support other children with lesser opportunities:

*There are many people like me who cannot see. I got the opportunity to study but there are many others who have not gotten this opportunity. So I want to go to rural places and teach them braille ... First, I have to study myself. And then I'll take help of the sir from here. And I'll have to make the people in the village aware about it.*

*IDI, 17-year-old girl who is blind, Khokana*

One girl, when asked about her future and specifically about marriage explained:

*Marriage is not everything. I want to study and stand on my own two feet and be independent.*

*Being a girl who is disabled, I want to work hard and prove the society wrong by doing something and succeeding in life.*

*IDI, 17-year-old girl who is blind, Khokana*

### 4.3 Coping with disability

Parents have to deal with a range of feelings and behaviours manifested by their child – including anger, sadness, anxiety, worry, and lack of confidence and self-worth. As mentioned, boys in particular start worrying about their ability to earn for their families as they get older. In response to this, caregivers said that they tried to give these boys hope and fortitude for the future, and encouraged them to stay in school:

*I then told him not to lose hope and focus on completing class 10 after that I will try my best to find you a job if we do not get a job then you start your own business. I told him education is not only about getting a job but to improve your knowledge and ability. I also told him to find other things to do such as singing and he can hone his singing skills and become a singer if he wants to, so there are lots of options for him.*

*IDI Brother-in-law of boy who is partially sighted, Khokana*

With younger adolescents and children, the main problems facing parents was helping them to manage their anger – for example, when they felt excluded by their peers. Parents approached this in a range of ways – from locking them in their room, talking to them, or giving them things to play with. When the disabled child comes home crying and angry, some parents lock the child in the room to help them cool down while other talk to them, take them for a ride, give them toys of their liking such as mobile phones to watch cartoons, take them to the park or spend time with them.

*Yes, but we don't have to be with him all the time. We take him to his room and give him a mobile phone or some toys to play games then he gets distracted for one to two hours and we then leave him in his room and go out.*

*IDI Father of boy with learning difficulties, Bhaktapur*

Families may also take children out of non-specialised schools and place them in specialised schools when available and with help from neighbours and other formal organisations. Isolating children from the rest of the community was also common, with caregivers not taking them to social gatherings. In these instances, caregivers often took it in turns to look after the child,

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with one caregiver, for instance, attending a social function while the other stayed at home with the child. Sending a child to the CBR centres so that family members, particularly mothers, could work is another approach, as was enlisting the help of siblings in the day-to-day care.

*In the mornings, I feed her breakfast and put on her clothes. I take her to toilet. [In the evening] I feed her dinner and make her bed.*

*IDI Sister of girl who is physically disabled (needs support to walk), Chakupat*

In cases where a child with disabilities has attended a specialised school and learnt sign language, caregivers have also learnt sign language and consult books provided to the child to better communicate with them. Some parents – largely fathers – have either left their business completely or remain partially engaged in order to look after their disabled son; some work from home and keep their child in their working area so as to be able to care for them. Others have left their non-disabled children in their maternal homes in the care of their own parents so that they can devote more time to their child with disabilities.

#### **4.4 Effects of earthquake on disability**

Most study respondents said that they were not greatly affected by the earthquakes. Those who were affected spoke of witnessing the ground shaking, and some mentioned cracks appearing in their homes. When asked how caregivers coped with their children with disabilities during the earthquakes, or how these children reacted during the disaster, they said that the children with disabilities were more scared and harder to manage than their non-disabled children. For this reason, parents were also more concerned and anxious about them:

*At the beginning she screamed about earthquake and when we requested her to come downstairs she ran away ... Since it shook a lot during that earthquake she cried a lot. I was downstairs with my son and she was upstairs. She ran through the stairs and came up to first floor. She almost fell through the stairs. Later she came outside by herself.*

*IDI Mother of girl with learning difficulties, Gwarko*

Caregivers noted that their immediate reaction during the earthquake was to rescue the child with disabilities as they assumed their non-disabled children would take care of themselves. Caregivers of children that were in specialised schools and hostels during the disaster were particularly anxious as communication was difficult for some time after and they couldn't ascertain their safety.

Caregivers also spoke of experiencing discrimination from their neighbours towards their child with disabilities during the earthquakes:

*She used to scream and everyone complained. To stay outside was our problem. We wanted security of our life rather than sleep ... I didn't like people complaining about my daughter so I told my husband that we better go inside home and die if the building collapse rather than listen to complains. Since mosquito problem was also there for sleeping so I used nets. When my daughter was inside the net she never ran out but she also didn't sleep. She just used to sit. During the aftershocks she used to scream a lot.*

*IDI, Mother of girl with learning difficulties, Gwarko*

Some key informants noted that, when they were living outside in tents or safe houses during earthquakes, disabled girls were particularly vulnerable to sexual abuse and harassment.

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# 5 Coverage and accessibility of the disability allowance

This chapter looks in detail at the coverage and accessibility of the government's disability card programme and related disability allowance, and at the effects of the 2015 earthquakes on this.

## 5.1 Programme coverage

### 5.1.1 Card coverage

The number of individuals registered for the disability card is documented on the government of Nepal's website.<sup>15</sup> At the time of writing, 62,894 people were registered for the profound disability card (red card) and 37,553 for severe disability (blue card).

There is, however, no clear documentation on whether all these card-holding individuals actually receive the disability allowance, or what proportion of people with disabilities should hold a card but do not, and are therefore excluded from the allowance (see also Banks et al., 2018). Reliable data is hard to obtain, but using what data there is available, our calculations suggest what the rates of exclusion might be.

Firstly, using the SINTEF data from 2014 and 2015, we find that the percentage of individuals who report having a disability but do not hold a disability card of any colour is 83%. For children with disabilities, this rate is slightly lower, but still concerningly high, at 78%.<sup>16</sup>

Of the disabled population who do hold a card:<sup>17</sup>

- 4% hold a red card
- 4% hold a blue card
- 6% hold a yellow or white card.

We also find that for those cardholders, the share of children with disabilities holding a red or blue card is significantly higher than the share of disabled adults (16% vs. 7%), and the share of children holding a yellow or white card is significantly lower (6% vs. 9%). This can partly be explained by the fact that children have more severe disabilities (higher mean activity limitation score and number of disabilities). However, even when taking this into account, we find that significantly more children hold a red/blue card than adults.

Data limitations mean this study cannot say what proportion of the 83% of individuals who do not hold a card should hold a red or blue card (and therefore be eligible to receive the disability allowance), but the figures suggest high levels of exclusion rates.

### 5.1.2 Allowance coverage

Using the SINTEF data, we find that of red and blue card holders, 58% of people with disabilities report not receiving the allowance (this is 43% for children). Again, this is a high exclusion rate. Disaggregating this data by age shows that the share of children with disabilities receiving a disability allowance is significantly higher than the share of adults with disabilities receiving it (10% vs. 6%, respectively). This may be explained by the fact that more children have a red or blue disability card. However, children with disabilities receive fewer other social security benefits than adults (2% vs. 12%), meaning that for children, the disability allowance is more important as a cash transfer than for other age groups. Thus, for disabled children, the disability grant is more important as a cash transfer than for other disabled age groups

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15 <http://www.docr.gov.np/Dashboard>

16 Both the quantitative and the qualitative analysis point to some inclusion errors in that small groups of people not having a card or having a yellow/white card but still receiving the grant.

17 Note that the question whether individuals have a disability card was only collected two weeks after the start of survey fieldwork. For 35% of the total sample of disabled the answer category is: 'Not applicable (not asked)'.

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(85% of disabled children receiving any social security benefit receive the disability grant, whereas this is 33% for disabled adults).<sup>18</sup>

While there are concerning errors of card holders being excluded from the disability allowance, the largest barrier to receiving the allowance is getting a disability card in the first place. We explore this further in the qualitative analysis in section 5.2.

### 5.1.3 Discrepancies in data

It is important to note, however, that data from other sources reveals different exclusion rates. Data from March 2017, shows that 199,490 Nepali citizens held the identification card for the fiscal year 2016/17 (Budhathoki, 2017). Of this total group, 37,285 held the red card and 49,077 held the blue card. Calculating this information with data from 2015 – which reported that 60,656 people with disabilities received a disability allowance (UNICEF, 2015) – suggests that approximately 30% of card holders who are eligible for the disability allowance are not receiving it.<sup>19</sup> This exclusion rate is much lower than that suggested by the SINTEF 2014 and 2015 data, but is still concerning. However, a recent report by Banks et al., (2018) - which also highlights the challenges in obtaining reliable data on programme coverage - using data from 2014/15 and 2011 census data, estimates 63% of people with disability do not hold a disability card, and that the disability allowance only reaches 12% of all people with disability.

These calculations suggest that whilst there are concerning exclusion errors of card holders to receiving the allowance, perhaps the largest barrier to receiving the disability allowance is getting a disability card in the first place. We explore these barriers further in the qualitative analysis below.

## 5.2 Applying for and receiving the disability card and allowance

### 5.2.1 Official application procedure for the disability card

As at January 2018, when we conducted the fieldwork for this study,<sup>20</sup> people with disabilities of any age can apply for a disability card free of cost at the Women and Children Development Office of the concerned district. The official application process to obtain the card

involves submitting an application letter to the social welfare officer through the respective rural municipality or municipality, together with supporting documentation including birth certificate, parents' citizenship certificate, certificate of land ownership, recommendations from a registered organisation working for people with disabilities, and other approved written documents.

An identity card recommendation committee is responsible for investigating incoming applications. The committee comprises individuals who have experience of working on disability:

- Chief District Officer (Coordinator)
- Planning Officer, District Coordination Committee (Member)
- District Health Officer (Member)
- Representatives from any of the organisation working in the disability sector and which is registered in the respective District Administration Office; National Disability Federation (Member)
- Women Development Officer (Member Secretary)

A government manual sets out guidelines for assessing and categorising disability, which the committee uses together with a doctor's certificate during an assessment meeting. This committee meeting is called by the women development officer as required, at least six times a year. The recommendation committee makes their recommendation to the women development officer who issues the card.

People with obvious severe disabilities (i.e. those who are blind or deaf, or have profound physical disabilities or learning difficulties) receive the disability identity card immediately before the committee meeting on the basis of a reference letter sent from their municipality to the Social Welfare Officer. The committee will then further endorse this decision. However, for those individuals whose disabilities are not as immediately obvious, they must first present a recommendation letter from a doctor to the recommendation committee, who will then assess the disability severity which will determine the colour of the disability card.

Once issued, the card is usually given directly to the person with disabilities. However, if they have severe disabilities and are unable to collect it, it may be given to a parent or caregiver if they provide a letter describing the situation and a recommendation from a local disability organisation.

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18 social security benefit (48%) than disabled children or disabled individuals of working age (12%). However, fewer elderly receive a disability allowance (5%) compared to disabled children (85%) or individuals of working age (54%) receiving any benefit. This is likely to be related to the fact that disabled elderly receive more often a social security benefit other than the disability grant (46% vs. 2% for disabled children and 6% for disabled individuals of working age). Disabled elderly receiving a social security benefit generally receive an old age pension (64%).

19 It is also worth noting, that according to NPC (2012) (cited in Chopra and Wadhawan, 2014) a total of 23,077 people with disabilities were receiving the Disability Allowance in 2011, suggesting that coverage of the allowance more than doubled in a five-year period (16,202 people were receiving the benefit for severe disability and 6,875 beneficiaries for the partial disability allowance (NPC 2012 cited in Chopra and Wadhawan, 2014)).

20 Note that we are using the names of Ministries and local bodies as they existed when we were doing our fieldwork in January 2018.

For those living in very remote places, they receive the card on the spot: a mobile team comprising of the recommendation committee members works with the rural municipality office to go to the ward offices to distribute the card. The team in such cases consists of a representative from district coordination office, a representative from the Women Development Office, a representative from public health office, a teacher from a local school and a member from any local organisation. In presence of the women development officer, the card can be issued from any place.

For all over Nepal in order to get the card, the applicant needs to submit three photos (with the disability visible in the picture if possible) – one to their respective municipality, one to the Women Development Office and one to the Social Welfare Office. Records of people with disabilities are kept in hard (printed) or soft (digital) copy by the Social Welfare Office, and by the Women Development Office, which reports to the Women, Children and Social Welfare Ministry every six months.

If a one needs to get the disability card reissued, individuals must obtain a recommendation letter from their respective police station or municipality, and submit this to the disabled identity card recommendation committee.

## 5.2.2 Application procedure for the disability allowance

To receive the disability allowance, the individual is required, once they have received the disability card, to go to the Ward Office and complete a form. With them they need to take a photograph, a photocopy of the disability card and their parents' citizenship documents. Children do not need to go, as the guardian named on their disability identity card can go on their behalf. People with disabilities can begin this process at any time, while for age-related allowances (i.e. pensions) there are specific timeframes.

Once registered, the applicant will receive a logbook in which to keep payment records. The ward submits the information to the district office, which then sends the information to the Ministry. National data on monthly cash transfers is held by the Department of Civil Registration (DOCR) under the Ministry of Federal Affairs and General Administration (MOFAGA) (formerly the Ministry of Federal Affairs and Local Development (MOFALD)).<sup>21</sup> This MIS database is only partially digitized, as many districts still submit data on hard copies. After that, the disability payment will come from the next payment schedule.

To receive the payment, the person with disabilities has to have a bank account opened in their name in the

designated bank. After that, the person with disabilities (or their caregiver on their behalf) has to go to the bank with a logbook to receive a cheque. The ward will have sent the details of the person to the bank as soon as s/he applies for the allowance.

## 5.3 Experiences in applying for and receiving the disability allowance

### 5.3.1 Applying for the disability identity card and allowance

Most respondents reported that they submitted the disability card application according to the official process, as described in section 5.2.1.<sup>22</sup> Most respondents applied for the card either at the VDC office, the Women and Children Development office in their respective districts, or the Ward Office.

A number of respondents who had moved away (for some children, because they were attending school further from home) noted that they had to travel to their home locality to obtain their card. For some, this meant taking time out of school, or not applying, as discussed further in section 5.5.

One other respondent said they travelled to the market where a government team had set up a distribution camp. It took a day for them to get the card and come back.

The length of time taken to apply for the card varied. For most, it took one or two days. In instances, where it took longer (more than a week or two) this was because they had to apply for other certificates and documentation at the same time, for which they had to go to up to three different places such as the ward office, the women development office and the hospital for the application. One respondent reported it took two months because the head officer was on holiday, and another said theirs took three months because the distance to the district office was far, and they had to go back to collect the card when it was done.

Respondents found out about the disability card and allowance in a number of different ways. The most common channels were CBR centres and schools. Indeed, CBR organisations are active players in the card application process,<sup>23</sup> sharing information and providing contact with relevant stakeholders for people with disabilities and caregivers:

*Officials at CBR told me about the card. Sharda didi from Women Development Office had come to CBR and they had organised a meeting at*

21 Note, that the Ministry of Women Children and Social Welfare does not collect or store data on government monthly cash allowance or disability. The Department of Women Children and Social Welfare maintains updated data on disability ID cards distribution.

22 Some respondents noted that they had to re-apply for their birth certificate or their parents' citizenship documents when applying for the disability card as they didn't have them.

23 CBR work in the card distribution where they are asked by the government to register the disabled, categorise them and write referral letters for them. In case when the disabled is unable to come to the office, they do home-visits and provide photos of the disabled to the government committee that approves the disability card. They also sit in the card approval committee (KII 6).

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*sunrise cafe and there she told us about the card. It was parents meeting [organised by CBR] and they told us what category of disability gets what card. We have officers from women development office, we have people from autism care so yes we have people from different organisations. They told us that those children who can no longer walk on their own will get a red colour disability card, and then he told us about who will get the blue coloured disability card and so based on what they said my son was eligible for blue or yellow coloured card I am not so sure. They also told us that based on the colour of the card the government gives certain amount grant money.*

*IDI, Mother of boy with learning difficulties,  
Lagankhel*

Some respondents heard about the card through officials at the VDC or Women Development Office (either formally or informally), and some through relatives or neighbours in their village. One respondent, who became disabled as a result of the earthquakes, heard about the disability allowance from disability organisations she had visited.

### 5.3.2 Receiving the disability allowance

While some allowance recipients from Lalitpur Sub-metropolitan city now receive their payments from the bank, others receive it in cash, directly from the VDC Ward Office. Some interviewees expressed concern that it may be difficult for people with disabilities to physically access the banks (KII 6,) compared to the special provisions which are currently in place such as the ward citizen forum or the VDC secretary bringing it to the recipient's house. Other special provisions for disability include card holders giving a power of attorney to someone else – the person is named on the disability card and can collect the allowance on behalf of the receiver.

Indeed, for the majority of our respondents, the parents or grandparents collect the money on their behalf. For those who no longer live in the same locality, they ask another household member – usually a grandparent – to receive the allowance on their behalf. A few respondents mentioned that the timings of the allowance payments coincide with pension payments, so both are often picked up at the same time (also mentioned in KIIs).

Families of children holding the red and blue card confirmed that they received the correct amount of allowance. However, the children were unsure of the amount received. Parents from Kathmandu Metropolitan City and Lalitpur Sub-metropolitan City also reported receiving a top-up of Rs 3,000 after earthquakes.

Most respondents confirmed that the allowance is paid regularly (two said that they experienced a delay at first – one for 'some months', and another for a year), with most

saying they received the allowance every four months and a few respondents saying it was every six months.

## 5.4 Use of the disability allowance

While some children with disabilities are unaware of what happens to the disability allowance once households receive it, others said that parents and caregivers decided what to spend it on, and noted several uses.

Most parents, concerned for the future of their child with disabilities, were reported to save the allowance:

*I have saved the money in the bank because he will need the money to take care of himself in the future. He will need that money when we will be not around for him in the future. When we die, his brother and sister might not care for him as us parents care for him, so if there is money in his name then they might want to care for him for the sake of money.*

*IDI Father boy with no hands or limbs, Khokana*

*The allowance money is for her so we don't use it for the house. It is for her future. If she has money then somebody will take care of her. We can use that money if she needs any medical care. But her father is spending his own money so we have not used her allowance money.*

*IDI, Mother of girl with epilepsy, Chakupat*

*In future when both I and my husband are not around then at that time this money will help her to take care of herself. We have saved it in the nearby bank.*

*IDI, Mother of girl with learning difficulties,  
Gwarko*

Other respondents said that the allowance is used to meet the child's needs – for example, to buy clothes, cover school expenses (including food, stationery, exam fees, etc.) and health expenses.

Quantitative analysis of the SINTEF data, on the other hand, revealed a different picture. In this survey, respondents did not report saving the disability allowance for the future, but said the money was spent on meeting more immediate needs.<sup>24</sup> Of all respondents with disabilities who answered this question, 62% stated that the allowance was mainly used to purchase household necessities (food, groceries, etc.), 17% said it was spent on clothing, and 12% said it was spent on rehabilitation and healthcare services. For children, these three categories were also the most popular first choice in answering this question (in

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24 Note that in the SINTEF survey, only 3% of all disabled individuals receiving the grant selected option 11- 'Other (savings; insurance; installed solar light)' – as their first choice in response to what the allowance is spent on. Only another 3% selected it as their second choice.

second choices, education (11%) appears). However, in our qualitative study parents from Kathmandu valley did say that they were saving it for the future of the children. This could also be because those in the Kathmandu valley are likely to have better access to income than people in rural areas and can save some money while those in rural areas spend it on immediate needs.<sup>25</sup>

## 5.5 Barriers to accessing the disability card and allowance

The quantitative analysis shows that several factors are associated with a higher probability of being assessed for, and receiving, a disability card (of any colour). These are:

- **the nature of the disability:** having a more severe disability, being disabled for a longer time, and having a physical disability
- **individual factors:** being male, of working age rather than a child or elderly, being literate
- **household factors:** living in a rural area, having a less diverse diet, living with a female household head
- **information availability:** being aware of health services.

Results from this data also show that a more severe disability is associated with holding a red or blue card, and with receiving the disability grant.<sup>26</sup>

During the study interviews and case studies, some respondents reported not facing problems in obtaining the disability card or accessing the allowance. However, in the context of the high exclusion errors outlined earlier in this chapter, these are in the minority.

For most others, challenges did exist. First, for those who have not applied for a disability card, one of the key reasons is the difficulty associated with applying back in their home ward/VDC.<sup>27</sup> In the case of one girl, who is deaf and non-verbal, the fact that she did not have permanent residency in the place of application prevented her from applying for the card (IDI, sister, Gwarko). For another girl – also deaf and non-verbal, her family does not have enough money to travel back to their home VDC to make the application (girl's father, Imadol). In one case, a boy with physical disabilities has to be present and return to the local VDC in order to apply, which is difficult for him to do (IDI, 16-year-old boy, Khokana).

One respondent was in the process of applying for the card in their current place of residence, but reported that they had been waiting to hear about the outcome for several months.

*I haven't gone back to inquire. I am originally from Jhapa but we had taken the migration certificate and moved permanently to Lele VDC so we had applied for it from Lele VDC. I have*

*though called the VDC office to ask them about the progress on my application and all they say to me is that it will take a bit of time.*

IDI, Mother of boy with learning difficulties,  
Lagankhel

Other reasons for not applying for a card include not knowing that the card exists, or a lack of clear information on how to apply, eligibility criteria, etc. While local civil society – such as ward citizen forums, citizens awareness centres, social mobilisers and teachers – play a role in sharing information, there is no official communication from the government about the allowance.

*In my opinion, they [people with disabilities or their family members] need someone who persistently tells them about it. We volunteers can't do that since we have to do our own work. I think that is the reason why most people are not aware of it ... First of all, they don't know about such facilities. And even if they know about it, they don't know the details. So, they need someone to tell it to them again and again so that it would be set in their mind.*

KII 9, Khokana

*No, I haven't [got a disability card for my son]. You need to have a permanent house/address to make a disability card and since we haven't been able to make it. My neighbours and fellow villagers told me this. Some say that I have to bring recommendation letter about my son's condition from my home VDC office, some say that I need to have my own house in order to be eligible to make the card. So, you tell me if I can never have my own house will I never be able to make a disability card for my son?... I don't know where I should go to get the right information regarding what I need to do to make a disability card for my son. I haven't [been to the local Ward Office] because I don't know what to do.*

*I also asked female teachers of this school and they told me that I have to go to my home VDC and get a recommendation from there and they said that they will help me complete the process. See I had made my citizenship before we sold our land....my husband is illiterate and so he is not a very clever person and so who should I talk to about these things and who should I turn to for suggestions.*

IDI, Mother of boy who is deaf and non-verbal,  
Khokana

25 A recent study by Banks et al., (2018) notes that the Supreme Court of Nepal recommended that the allowance for red card holders be Rs. 5,000.

26 Sample size is low for analysing hurdles for receiving a red or blue disability card compared to a yellow and white card, and for receiving a disability grant if the disabled individual holds a red or blue disability card.

27 This challenge could be specific to our sample of interviewees who have migrated to the Kathmandu valley.

Figure 1 Key barriers to accessing the disability card and allowance



Note: VDC was the term used by the respondents

## DOCUMENTATION PRESENTED AT VDC



### BARRIERS

- The difficulties obtaining the correct documentation to apply for the card (including citizenship documents)
- The difficulties associated with applying in home village if they are living elsewhere, especially if this means taking children out of school to apply



## ASSESSMENT AND DECISION MAKING ON TYPE OF CARD



### BARRIERS

- Challenges in the assessment phase, including lack of clarity on how the assessment guidelines are interpreted to assess disability, and concerns of corrupt practices

The daughter of another respondent was denied the card at the assessment stage:

*[The Women's Development Office] told me 'If [she] can learn what she is taught so we are not giving her any card'. But I told them that wherever she goes that kind of ID card is asked from her. She needs so much medicine, it is very expensive for us to buy medicine for her. Wherever I go they seek the ID card. I requested them to offer the first group card.*

IDI, Mother of girl with epilepsy, Bhaktapur

Indeed, despite the availability of the government's assessment guidelines, the assessment process is often complex and subjective – especially where disabilities are not readily observable. Respondents also reported problems with receiving cards for individuals with learning difficulties, whose impairments are not always observable. As one KII noted, in some cases, district public health office doctors who have to give the referral know little about learning difficulties and do not want to categorise these individuals as 'disabled'. As such, they may hesitate to refer people with autism, haemophilia, or have learning difficulties where disability is not evident. There is no system to identify these sorts of disabilities, nor have doctors received awareness training on them (KII 4).

One KII suggested that in some cases there is corruption associated with the assessment and allocation of card:

*Disabled people who are eligible to get [a] red card according to severity sometimes do not get it. There are few cases like this and it might be due to political and other kinds of pressure. We can say that either it is corruption or unfair distribution.*

KII 3

Of our respondents, only a few red or blue card holders had not received the disability allowance. For some, this was because they had only just received the card. For one respondent, however, he hadn't received the allowance because he didn't register his name at the time of receiving the card, and it is too difficult now for him to return to his village from Kathmandu to do so. This 15-year-old boy had already spent two months in the village while the card was being issued (because the Ward Officer was away), and had missed school during this time (IDI, 15-year-old boy who is blind, Bhaktapur).

Though other respondents had by the time of interview received both the card and the allowance, they explained that this was not without difficulty. When at first her daughter was denied a card, one mother had to argue the case:

*When I took her there she played with a doll that I bought for her in Khadichaur. She also greeted inspector there. Then the inspector denied to give red card to her as she seemed more active. Inspector*

*thought she was normal. I argued with her as I had people there. I said if she was ok, why would I take her there to make card. She cannot walk.*

IDI, Mother of girl with learning difficulties,  
Gwarko

In a similar case, another mother reported:

*[The] teacher had an argument about my child's condition with the doctor. The teacher challenged the doctor to come to CBR and observe her condition. She also bargained that since the amount was very little, there was no point for them to make such effort without the need of the child and asked the doctor that why they would lie for such small amount. So the doctor finally gave the card.*

IDI, Mother of girl with learning difficulties,  
Gwarko

Another key challenge raised by respondents was having to obtain all the correct documentation (e.g. birth and marriage certificates) required to apply for the card. This was also highlighted in a key informant interview with a representative from the Nepal Disabled Women Association, which works with orphans with disabilities:

*We still have to make citizenship and ID card for her (the orphan they found when she was 6 or 7 years old). She doesn't know anything about her parents etc so we told authorities that her home is at Sindhupalchowk. We have another woman with similar case but older. We named her Bharati and we brought her from Kanchanpur.*

KII 3

A couple of respondents also complained about the long waiting time for the application, especially as this meant children might need to miss school (as in the case of the 15-year-old boy, mentioned earlier in this section).

Some challenges related specifically to the process of applying for the allowance. For example, some respondents noted the additional administrative burden of applying for the allowance having already applied for the card, as well as a lack of clarity and information about how to apply.

*I haven't registered my name in the VDC so I don't get an allowance. I'll have to do it later as I just made the card some time ago. I got my card late on the 24th and I had to come here immediately. The VDC of my house was separate from the one of my maternal uncle's. Also it was very far. About half an hour to one hour away. So I did not go there. Also I had to photocopy the card and things like that. My uncle was also busy.*

IDI, 15-year-old boy who is blind,  
Bhaktapur

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*There will be problems [in taking the allowance]. I haven't taken the allowance till now so I will have to search for people who will give me information about the allowance. I have to ask about it in VDC. [But] the VDC people might not be easily accessible. They might not come daily to the VDC office. The VDC office might be closed when we go there.*

*IDI, Father of boy who is deaf and non-verbal,  
Khokana*

Beyond the application processes, challenges were also reported in the process of receiving the allowance.<sup>28</sup> Some respondents mentioned that they faced long queues when collecting payments at the bank or the VDC distribution point. Some also reported a lack of information about when they would be able to collect the allowance, and said they relied on other people to communicate this (particularly those receiving the other social security allowances who tend to know when it is being paid).

However, one key informant from Khokana disagreed, saying that information is spread relatively quickly and accessibly to the relevant wards. They explained that a notice is circulated to each ward and sends messages through the 27 ward citizen forum members. Since the ward is a small place, information is quickly spread by words of mouth, and people tend to have collected the payment within 2 to 3 days at most (KII 9, Khokana).

## 5.6 Effects of 2015 earthquakes on the disability allowance

Only two respondents reported delays in the distribution of the disability allowance after the 2015 earthquakes, and these delays were resolved when the offices started functioning again after the earthquakes. One respondent who started receiving the allowance after the earthquakes said that they received the allowance four months after applying, but this is no different from some other respondents who confirm that they receive the allowance three times a year.

A few respondents in fact said that the earthquakes didn't have any effect on the allowance – either in terms of issuance of payment or loss of their documentation.

This was corroborated by KIIs, who reported that there was no negative effect on programme delivery (KII 6, Bhaktapur) (although there were challenges with programme coordination due to the large numbers of actors operating in disaster relief (KII 6, Bhaktapur)). Additionally, our data shows that there was no significant loss of documentation (KII 10, Khokana). Indeed, the Ward Office can issue a replacement card if the old card is lost, and this is relatively easy as the office keeps photocopied records of all the application documents (KII 10, Khokana).

Another KII mentioned that the disability allowance was not a priority for families affected badly by the earthquakes, reporting that people had left their place of origin and went back only after a long time to collect the allowances (KII 4).<sup>29</sup> Indeed, caregivers were more occupied with managing their day-to-day life in temporary shelters and protecting their children from aftershocks; going back to collect the allowance was not a priority (KII 4).

In the case of the individual who had been newly disabled due to the earthquakes, she reported applying for the disability allowance at the Women and Children Development Office after a number of organisations she visited told her that she would receive an allowance. However:

*My father even went to VDC office to enquire about it and they said that the earthquake victims don't get grant and the ones with yellow card also don't get the grant.*

*IDI, 17 years girl with double leg amputation,  
Nepaltar*

In addition to these qualitative findings, the quantitative analysis did not reveal any evidence that the probability of being assessed and having a disability card of any colour is different in the areas affected by the earthquakes in 2015, or in areas that were affected by flooding in August 2014. However, we do find that individuals with disabilities who are living in poorer quality housing (and are therefore potentially more vulnerable to the physical effects of earthquakes or floods) have a lower probability of being assessed and receiving a card.

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28 Also add in issue of quotas

29 Also note that the Ward Office have to return the money back to the DDC and hence people did not get the allowance if they went late to the wards. There is a provision that one can apply for it in the next instalment, but many people are not aware about it (Ibid).

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# 6 Conclusion and policy implications

## 6.1 Conclusions

### 6.1.1 Summary of key findings on experiences of disability

Our study on children with disabilities and their family members illustrates a wide range of experiences, emotions and challenges associated with disability. These findings, and the challenges that children and their families face, are similar to those reported in other recent studies on disability in Nepal (for example, see Banks et al., 2018; Devkotal et al., 2017; Eide et al., 2016; HRW, 2011; Lord et al., 2016).

Children and their caregivers reported that they felt more stigma or discrimination in rural areas than urban areas towards children with disabilities. This was explained by the fact that there were fewer people with disabilities in these rural areas, a more limited awareness of their needs and fewer appropriate services and infrastructure. By contrast, in urban areas, increased awareness and the opportunity for persons with disabilities to mix more with their peers was associated with a feeling that discrimination against them was less.

Both children with disabilities and their caregivers raised concerns for the psychosocial wellbeing of boys and girls with disabilities. Here there was also a distinct gender dimension, with caregivers seeming more concerned about the safety of girls with disabilities as, according to them, they are more vulnerable to abuse and violence than boys. For boys, social norms around their role in providing for their families and households drove their worries.

A specific area of concern that caused anxiety and worry for many caregivers was what would happen to and who would care for their children with disabilities when they died or were no longer to take care of them. In examining education opportunities for children with disabilities, a concerning pattern of high drop-out rates emerges. We found that many such children – largely in rural areas – had dropped out of non-specialised school due to their disability. The reasons for this were numerous. One key reason is the fact that in rural (and to some extent, urban) areas, these children report finding it difficult to study, to concentrate, to follow

in class. Falling further behind in their schooling, they feel they cannot cope. Other factors, such as being teased by peers, exclusion from play-related activities, or punishment from teachers for underperforming, also contribute to children dropping out, as does the lack of appropriate infrastructure and facilities. Key informants noted that this last factor often affects girls with disabilities more than boys with disabilities.

Children from poor households face additional challenges. Respondents noted that poor parents who have to manage with scarce resources give less priority to send their child with disabilities to school, as they usually would need to spend more for them than other children. They do not believe that a disabled child can take the duty of a breadwinner later on. As such, education is often not a viable option for children with disabilities who live in poor households. Girls may be particularly vulnerable in this regard: parents often do not send girls with disabilities to school, believing that it will be hard to ‘marry off’ a girl with disabilities there is little value in investing in her education. For boys, however, parents still hope that they will be able to earn something for them in future.

Disability also has significant economic impacts for a household. Direct impacts come from added expenditure on healthcare – including the regular medication that some children need – along with costs related to specialised care and assistive devices, and/or the loss of a parent or guardian’s job or economic activity as they take on the role of caregiver. Several parents noted that assistive devices for those who cannot hear are the most difficult to afford, while some respondents said that certain assistive devices were provided free of charge by particular hospitals – such as by the Hospital and Rehabilitation Centre for Disabled Children in Banepa. For people with physical disabilities, hospitals provided wheelchairs, prosthetics and crutches. Some partially sighted individuals purchased a magnifying glass (\$12) themselves as it was not free.

Until recently, the Nepal Disability Fund in Kathmandu (run by the Social Welfare Council) also provided free devices and device maintenance for earthquake-affected people. However, this stopped a few months prior to our fieldwork. Parents of children with

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learning difficulties seemed to have spent less. However, some interviews revealed that parents of children with multiple disabilities spend more money as they need regular medication. While those who have disability cards receive a discount on medicines, those without cards have to pay the full amount.

### 6.1.2 Summary of key findings on the disability allowance

People with disabilities who hold a red or blue disability card – denoting ‘total’ disability or ‘severe’ disability, according to the government’s assessment criteria – are eligible to receive a government disability allowance. Red card holders receive an allowance of Rs 2,000 a month (\$19), while blue card holders receive an allowance of Rs 600 (\$6) a month.

Findings from our qualitative interviews in Kathmandu valley with the parents of children with disabilities who had a disability card and received the allowance reported that they either save the money for their children’s future (especially given their concern about will happen to their children when they are unable to care for them) or spend it to meet the child’s immediate needs – for example, to buy clothes, cover school expenses (including food, stationery, exam fees, etc.) and health expenses.

The quantitative data analysis suggests that the disability allowance is a particularly important cash transfer for children with disabilities – as compared with other disabled age groups, who may also receive other social security benefits.

While many parents interviewed for this study reported that their application for the disability card and allowance only took a few days and that they receive the correct amount of their allowance regularly, they did note a number of challenges in the process of applying for and receiving the card or allowance. These findings reflect similar findings emerging from other recent studies on the disability card and allowance (for example, see Banks et al., 2018; and Lord et al., 2016). The following are the key findings from the quantitative and qualitative analysis on barriers to accessing the disability allowance.

First, is the issue of exclusion from receiving a disability card (and thus the disability allowance). While reliable data is difficult to obtain, secondary data and an analysis of SINTEF (collected 2014 and 2015) data suggest that there is a high level of exclusion error for people with disability not holding a disability card. For instance, the SINTEF data shows that across all individuals with disabilities (including children), 83% do not hold a disability card of any colour.<sup>30</sup> Interestingly, analysis of the SINTEF data also reveals that certain factors are associated with a higher probability of receiving a card (of any colour). These are:

- the nature of the disability: having a more severe disability, being disabled for a longer time, and having a physical disability
- individual factors: being male, of working age rather than a child or elderly, being literate
- household factors: living in a rural area, having a less diverse diet, living with a female household head
- information availability: being aware of health services.

Secondly, is exclusion from the disability allowance, even for individuals already holding a red or blue card. Data from UNICEF (2015), for example, reported that 60,656 people with disabilities received a disability allowance (UNICEF, 2015). Along with data on red and blue card holders from Budhathoki (2017), this suggests that approximately 30% of card-holding people with disabilities who are eligible for the disability allowance are not receiving it. Drawing on the analysis of the SINTEF data, we see even higher levels of exclusion errors, with only 42% of eligible card-holders indicating that they receive the disability allowance (suggesting an exclusion error of 58%). The qualitative data offer some explanations as to why these exclusion rates are so high.

The qualitative data shows that one of the reasons why households of children with disabilities do not apply for the disability identity card is the difficulties associated with applying back in their home village development committee (VDC). For one individual, the fact that she did not have permanent residency in the place of application prevented her from applying for the card. For another, her family did not have enough money to travel back to their home VDC to file the application. In one case, the child had to be present and return to the local VDC to apply. Other reasons for not applying for a card included not knowing that the card existed, and a lack of clear information on how to apply, including eligibility criteria, etc.

Some respondents were denied a card at the assessment phase. Key informants and some parents of children with disabilities said that the lack of clear guidelines and complexity of assessing disability is a challenge. For example, in instances where a child did not show signs of physical disability, there were reports of being denied the card. Some interviewees attributed this to limited knowledge among doctors or the assessment committee, while others suggested that in some cases allocation practices are corrupt.

According to study respondents, not receiving the allowance was due to the additional administrative task of registering their names with the VDC – e.g. there is no automatic link between receiving the card and receiving the allowance.

Even respondents who received both the card and the allowance reported challenges – including those already mentioned. Another parent said that, at the assessment

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30 Both the quantitative and the qualitative analysis point to some inclusion errors in that small groups of people not having a card or having a yellow/white card but still receiving the grant.

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stage, they were at first denied a disability card, but argued the case and won. Another key challenge mentioned by respondents is having to obtain all the correct documentation (e.g. birth and marriage certificates) to complete the card application; for those who do not have documents, the application process is more difficult. This was also highlighted in a key informant interview with an organisation that works with orphans with disabilities.

Beyond the application processes, respondents also reported barriers to receiving the allowance itself. Some respondents mentioned that they faced long queues when collecting payments at the bank or the VDC distribution point. Some also reported a lack of information about when they would be able to collect the allowance, and said they relied on other people to communicate this (particularly those receiving the other social security allowances who tend to know when it is being paid).

### 6.1.3 Summary of key findings on the effects of the 2015 earthquakes

Families who were affected by the earthquakes in 2015, reported that they witnessed the ground shaking, and some were affected spoke of witnessing the ground shaking, and some mentioned cracks appearing in their homes. When asked how caregivers coped with their children with disabilities during the earthquakes, or how these children reacted during the disaster, they said that the children with disabilities were more scared and harder to manage than their non-disabled children. For this reason, parents were also more concerned and anxious about them. Indeed, caregivers also reported that their immediate reaction during the earthquake was to rescue the child with disabilities as they assumed their non-disabled children would take care of themselves. Caregivers of children that were in specialised schools and hostels during the disaster were particularly anxious as communication was difficult for some time after and they couldn't ascertain their safety. Importantly, some key informants noted that, when they were living outside in tents or safe houses during earthquakes, disabled girls were particularly vulnerable to sexual abuse and harassment.

Only two respondents reported delays in the distribution of the disability allowance after the 2015 earthquakes, and these delays were resolved when the offices started functioning again after the earthquakes. Most respondents in fact said that the earthquakes didn't affect receiving the allowance – either in terms of issuance of payment or loss of their documentation. This was corroborated by KIIs, who reported that there was no negative effect on programme delivery (although there were challenges with programme coordination due to the high level of actors operating in disaster relief). The key informant interviews also revealed that there was no significant loss of documentation. Indeed, it was reported that the Ward Office can issue a replacement card if one is lost, and this is relatively easy as the office keeps photocopied records of all the application documents.

Another key informant interview explained that the disability allowance was perhaps not a priority for families affected badly by the earthquakes, reporting that people had left their place of origin and went back only after a long time to collect the allowance. Indeed, caregivers were more occupied with managing their day-to-day life in temporary shelters and protecting their children from aftershocks; going back to collect the allowance was not a priority.

As such, when thinking about strengthening the shock-responsiveness of the SSA system, our study findings and the recent evaluations of the ECTP indicate that the most pressing issues for the disability allowance are around accessing the disability card scheme (UNICEF, 2015; Merttens et al., 2017). Indeed, challenges of the high exclusion rates from the disability card – and thus allowance – suggests that significant efforts must be made to overcome exclusionary barriers if the disability allowance is to be made more shock-responsive. This is also especially important as it applies to children with children, given the relative importance of the disability allowance for such children.

## 6.2 Policy implications

Based on the analysis of the study's findings, we provide the following key policy considerations for improving the accessibility and effects of the allowance, including in the context of shocks:

### 1. Raise awareness and improve communication on the disability card and allowance to reduce the high levels of exclusion from the disability allowance.

This includes improving awareness-raising activities around the disability card and allowance. This may be done by, for example communicating clear and easily accessible information about the eligibility criteria and the process for applying for both the card and the allowance through a range of different forums (community meetings/gatherings, at clinics, in schools, through parents and teachers associations), and training ward members, social mobilisers and other community leader to communicate relevant information. Consideration should be given to ensure that severely disabled individuals and their families can access this information.

### 2. Improve the disability assessment process.

This could include clarifying the 'grey areas' – for example, what to do when disabilities being assessed are not obvious or observable. The new draft bill has addressed this by maintaining 'intellectual and cognitive disability' (learning difficulties) as a category, but we are yet to see its implementation challenges being addressed. Another option is to provide regular refreshers to the assessment committee members, organising more

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assessment camps, and ensuring that people with disabilities can access the assessment committees.

### **3. Simplify the procedure for receiving the disability allowance.**

Consider automatically enrolling red and blue card holders to receive the allowance (e.g. taking all the necessary details at the time the card is given to the beneficiary).

### **4. Simplify procedures for applying in current locality.**

Steps should be taken to enable people who are not living in their original home locality to apply for the card and allowance where there are currently residing.

### **5. Ensure that infrastructure and services are accessible to people with disabilities.**

For example, ensuring that banks are accessible to the disabled (e.g. braille is made available in the current transaction system for those people with sight impairments, and ATMs and banks are accessible by ramp for those with physical impairments), and that continued support is provided to people with disabilities who are unable travel to the bank or ward to receive the allowance.

### **6. Coordinate and make use of complementary programmes and services.**

Many people with disabilities and their families reported that their wellbeing is also affected by stress, anxiety and worry about disabled children and their future. Opportunities should be explored to coordinate and link

with other service providers such as CTEVT to ensure people with disabilities have access to livelihoods and life-skill supports, and other necessary services.

### **7. Support the capacity of local service provider in the municipalities and rural municipalities to deliver services for people with disabilities.**

This includes increasing the technical skills needed to assess disability for the disability card and developing a grievance and redressal service for those who are denied a disability card or experience problems with the delivery of the disability allowance. This also means ensuring that the policies designed to support individuals with disabilities are implemented (especially in rural areas) and increasing access to services and programmes which include easing the financial burden of costs associated with disability (e.g. healthcare, assistive devices, etc).

### **8. Invest in data collection and analysis.**

Investment is needed to improve data availability of people with disability, the disability card and the disability allowance. Currently, data is not digitised or disaggregated by age at the federal level. Better data would improve programme design and delivery, and inform future shock-responsive adaptations at federal, provincial and local levels. Consideration should be given to adopting rigorous methodologies in both administrative and household surveys, such as the Washington Group Questionnaire, to measure disability.

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# Annex 1 List of respondents

## Key informant interviews

KII 1	KII with Secretary, National Disabled Association of Nepal
KII 2	KII with HOD, Social Inclusion Department, Ministry of Education
KII 3	KII with Secretary of Nepal Disabled Women's Federation
KII 4	KII with President of Parents Federation of Disabled Children
KII 5	KII with Section Chief, Social Inclusion Section, Ministry of Women Children and Senior Citizen
KII 6	KII (duo) with Program Manager, Community Based Rehabilitation Centre, Bhaktapur and Chairman of RCRD Bhaktapur
KII 7	KII with Program Manager, Community Based Rehabilitation Centre, Lalitpur
KII 8	KII with Section Head, Social Inclusion Division, Ministry of Federal Affairs and General Administration
KII 9	KII with member of Ward Citizen Forum, Khokana
KII 10	KII (duo) with Ward Chairman and member of Ward Committee.

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# Annex 2 Key sectoral policies for people with disability

## Education

- a. Free higher education service: A person with any kind of disability can get this facility if he has a disability card. This facility is provided by Tribhuvan University (the government university in Nepal) and its affiliated colleges.
- b. Free education in school: There is a provision of free education to children with all kinds of disability in all government and community schools. To get this facility, a child should submit a copy of his disabled identity card to the school.
- c. Scholarships (provided on the basis of yearly plan and program of the Ministry of Education): Any children with disabilities of school-going age from grade 1-10 are provided with the scholarship money. The amount of money is distributed according to the type of disability a child possess. The amount ranges from \$0.5-20, per month. This facility is provided by local government in lower secondary to secondary level schools under district education office. The scholarship can also be provided through locally working NGOs. Besides this, there is a provision that all private school must have 5% reservation seats for scholarship to the poor, disabled, female, dalit and janajati students.
- d. Special education provision: This facility is provided to those children (especially the deaf, blind and intellectually disabled) who need special type of education for equal opportunity in education. This facility is available in different districts from the local non-governmental organisations who get sponsored by the Education Ministry and also from the Tribhuvan University, Education Ministry/Special Education Council.
- e. Scholarship in technical education and vocational training: A person with disability is provided scholarship in the training program organized in the Council for Technical Education and Vocational Training, (CTEVT). Any branch offices or affiliated organisations of CTEVT provides total of 6 scholarships per sessions. Each scholarship amounts to \$50 per person.
- f. Provision of additional facility during exams: There is a time addition up to 1 hour and 30 minutes in normal exam hours for children with disabilities (to those who are slow to do their work or have low physical performance level due to their disability). If the person is blind, then there is the provision of an assistant to write on their behalf.
- g. According to the Nepal Government Scholarship related policy, 2021, there is a provision of scholarship to the students for higher education on a competitive basis where there is reservation of certain seats for the students with disabilities. The amount and seats are based on annual budget allocation.

## Health

- a. Free health Services (mentioned in the law): This free health service is provided to all disabled people of all the 4 categories. It is provided in all government health centers or hospitals. The person wishing to get this service should submit their disability card in place of money in the cash counter in a hospital.
- b. Reservation of bed in hospital: There is a provision of reservation of certain number of beds for disabled people in all Government Hospitals throughout the country. A person needs to show his disability card to get this service.
- c. Discount and free medicines: There is a provision for free medicines (limited number of medicines – 41 types) to disabled people in government hospitals. A person wishing to get this service should show their disability card to get the medicines after check-up in the government hospitals.

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## Employment and income generation

- a. Reservation: disabled people recognised by the government are provided with 5% reservation seats in civil service by the central office of public service council and its zonal headquarters. Additional 5% seats are reserved in Nepal Telecom, Radio Nepal (permanent service), education services for disabled people. The government also directs private sectors to reserve 5% seats for disabled persons.
- b. Special facility for disabled employees: if a person becomes disabled during their civil service period and is not able to continue his work due to their disability, they will be provided with financial support, retirement with special relief and special holidays. These facilities are provided by General Administration Ministry.
- c. Discount in tax: Government of Nepal has provisions for reduction of up to 50% tax for disabled people than for others. Tax is not imposed to a married person who is disabled and who earns up to \$3,000 annually.
- d. Employment opportunity for blind people: the Ministry of Industry and Commerce provides training and job opportunities for blind people.
- e. Special provision for disabled people: if a person in civil service is unable to continue working due to certain physical or mental health conditions, then his/her total working period is added by 7 years and s/he gets retirement with special provisions.

## Training

- a. Free commercial training for disabled people: For the economic empowerment of people with disabilities, commercial training is provided for free by different organisations, such as the Women, Children and Public Welfare Ministry, CTEVT and its local training centres, Department of Cottage and Small Industry, District Development Committees, District Agriculture Committees and the non-government organisations working in the disability sector. Besides this, there is also provision of free journalism and anchoring trainings for disabled people under these institutions.

## Mobility

- a. 50% discount on domestic airfare for disabled people
- b. 50% discount on public transportation for disabled people
- c. Seat reservations on local transportation for disabled people
- d. Special tax discount on the 4-wheeler scooter designed for disabled people and also additional provision of discount in the VAT amount in purchase of such vehicles
- e. Space to keep wheelchair on public transportation

## Physical accessibility

- a. Make special provisions (such as ramps), placement of bolts and locks in doors in disability-friendly way, spaces for keeping wheelchairs for physical accessibility of disabled people in the public infrastructures. All new public infrastructure to be constructed should have disability-friendly infrastructure.

## Rehabilitation, empowerment and social security

- a. Reduction in the tax amount for the assistive materials (such as artificial leg, hearing device, wheelchair, etc.) for disabled people.
- b. The assistive material is provided by the government to disabled people for free.
- c. Budget is provided to the Rural Municipality and Municipality by the Ministry of Federal Affairs and General Administration by for the development and support of disabled people. In the earlier system, it used to go from the Ministry of Federal Affairs and Local Development to the District Development Committee, from where it used to go to the different wards through the Village Development Committee or Municipality.
- d. Provision of accommodation to disabled people who are homeless.
- e. Provision of orphanage, rehabilitation and mental hospitals/centres
- f. Provision of financial support and education allowance, etc. for policemen who become disabled during their service tenure.
- g. Special financial support and disabled allowance to policemen (and Maoists combatants for those disabled by the Maoist war).
- h. Special discount (25%) land ownership registration for disabled people.

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## **Sports and entertainment**

- a. Provision of organising Para-Olympic games and special games for disabled people for their empowerment and development. The Youth and Sports Ministry organises different sports competition programmes in collaboration with young people with disabilities.

## **Legal support**

Free legal support (such as legal counselling, document preparation to present in the court) by the government when necessary.

## **Community-based rehabilitation programme run by the Government of Nepal**

Nepal Government Women, Children and Welfare Ministry has been running a community-based rehabilitation programme for the empowerment and development of disabled people since 2001–2002 in different districts.

# Annex 3 Service providers in case study locations

Organisation	Objective	Target group and coverage	Programmes	Structure, partnerships, funding
Community Based Rehabilitation (CBR) Centre in Bhaktapur and Patan; in Bhaktapur the RCRD is linked to the CBR	<p>Three <b>objectives</b>:</p> <ol style="list-style-type: none"> <li>1. CBR of disabled children</li> <li>2. Documentation of policies and works on raising</li> <li>3. Bringing together different organisations working on different types of disability under one umbrella for advocacy.</li> </ol>	<p>Their main <b>target group</b> for CBR are disabled people including children and adults. They cover all kinds of disability.</p> <p>In terms of <b>coverage</b>, they run the CBR in Bhaktapur district; their awareness raising and advocacy covers the whole country.</p> <p>In the CBR work, in 2017 they supported 350 beneficiaries through different programmes.</p>	<ol style="list-style-type: none"> <li>1. <b>CBR</b> – consists of weekly home visits by trained social mobilisers to severely disabled children for basic education, physiotherapy and life-skills for the children and parenting training for the carers. The programme also links partially disabled child to specialised health and education services and provides assistive devices.</li> <li>2. <b>Policy advocacy work</b> – provides feedback when the government calls them in policymaking meetings.</li> <li>3. <b>Support the government</b> in the disability card distribution – register, categorise and write referral letters for disabled people; if they are unable to come to the office, home-visits and photos are provided to the government committee that approves the disability card. They also sit in the card approval committee.</li> </ol>	<p>CBR is involved with the following <b>two committees</b>: National CBR coordination committee run by the Ministry of Health and the National Inclusive Education Network Committee run by the Ministry of Education.</p> <p>Other <b>stakeholders partner</b> with: UNICEF, Planning Commission, District Administration Office, District Public Health Office, District Hospital, Women and Children Development offices, District Development Committee, and NGOs e.g. World Education working on disability.</p> <p><b>Funding</b>: previously UNICEF and Save the children; currently Gov of Nepal through Ministry of Women, Children and Senior Citizens, District Development Committee, District Education Office. Every year it provides approximately 5million NRs. Also receive occasional funding from I/NGOS and individuals in both cash and kind.</p>

Organisation	Objective	Target group and coverage	Programmes	Structure, partnerships, funding
Ward Citizen Forum	<p>The ward citizen forum is a civil society committee for local governance; provision for the committee was made by the government and it exists in each ward. Members, of which there are 27 and are drawn from the community with representation of men, women, adolescents, older people, etc. are voluntary</p> <p>Their main <b>objective</b> is to help connect local government structures to the people, prepare plan and budget for the wards.</p>	<p>Their main <b>target group</b> is all people in their wards including people with special needs such as disabled people, senior citizens and other disadvantaged groups.</p>	<p>For <b>disabled people</b>, main tasks included: informing people about the allowance distribution dates, helping in the distribution and taking the allowances to a disabled person's home if the person was not able to come to the ward office.</p> <p>The committee meets monthly, the main task is to collect demands and propose the community needs to the ward office. These may include issues related to drinking water, road construction, awareness programmes, women empowerment programmes, programmes for disabled people, children's playgrounds etc. They then prepare a budget and plan. The ward allocates 10% of the budget each year for disadvantaged people including those with disability and they also look for funding from other donors. After the new elected representatives, the committee has now been dissolved.</p>	<p>They work with Government, the ward office and donor NGOs.</p>
Ward office, Khokana	<p>Ward offices are local structures of the Municipality.</p>	<p>Their <b>target group</b> are all community members who receive government services, including disabled people and other groups who receive social security allowances (SSA)</p> <p>Overall there are 400 allowance receivers in the ward and among them 20 receive disability grants. All the disability allowance receivers are over 20 years of age. Three have red cards and the rest have blue cards. There are 12 men and 8 women who receive the disability grant in the ward.</p>	<p>The SSA programmes started in 1993 in Khokana as a programme for senior citizens. It was extended to widows and disabled after 1994.</p> <p>Regarding the disability grant, the ward supports in identifying and compiling the needs of disabled people and presenting a plan to the municipality/rural municipality. The ward also is in charge of registering disabled people, changing or renewing lost cards and the distribution of grants - though recently the transfer now happens through banks so they no longer have this remit. They are not involved in the categorisation disabled people according to card colour, nor do they make the cards. The cards are made in the Office of the Women and Children Development which is the district line agency of the Ministry of Women Children and Senior Citizens and has mandate to address needs of disadvantaged people including those with disabilities (for further details of the modalities in which they work see section 5).</p>	

Organisation	Objective	Target group and coverage	Programmes	Structure, partnerships, funding
Disabled Service Association	<p>The disabled service association started in 1997.</p> <p>The main <b>objective</b> is to help disabled children with education and life skills and prepare and keep them in integrated schools for higher education. It also provides shelter and out of school classes for the disabled children.</p>	<p>Their <b>target groups</b> are children with disabilities from all over Nepal; they do not take children with mental health conditions. They prioritise children on the basis of needs; hence children who do not need wheelchairs, sign language, braille and those who can go to schools in their community are not given places in the hostel. Children also need to have ID cards.</p> <p>Currently they have 65 children, 55 stay in the hostel and 10 live nearby and travel to the hostel on a daily basis.</p>	<p><b>Programmes/activities</b> include looking after children in the hostel, giving them life-skills trainings and connecting them to specialised kindergarten programmes and the integrated higher education system. It also gives training to teachers to teach deaf and blind children.</p>	<p><b>Funders</b> have included INGOs (e.g. Zalopp Foundation from Switzerland), UN peace keeping force, individuals who give cash, materials and scholarships for children.</p>
Ministry of Education (Social Inclusion Department)	<p>The department is responsible for all aspects related to inclusive education (which started 15 years ago in Nepal) for disabled children, street children, girls, socially disadvantaged and others.</p>	<p>The target groups are children with disabilities and education systems within the government. Nearly 60,000 children receive scholarships per year, among which 7,000 children receive residential scholarships and around 3,000 children receive the assistance scholarship so far.</p> <p>They have approximately 600 trained teachers working in government schools all over the country.</p>	<p>They have the following cash transfers and other services for the disabled children:</p> <p><b>Scholarships:</b> i) Residential scholarships; ii) Scholarship for assistance; iii) Transportation scholarship; iv) Motivational scholarship and v) Higher education scholarships:</p> <p><b>Resource classes:</b> there are 380 resource classes which prepare disabled children (deaf and blind) to enter regular classes.</p> <p><b>Integrated schools:</b> there are 23 of these in Nepal, are all secondary.</p> <p><b>Behaviour change classes:</b> For children with mental health conditions.</p> <p><b>Master's and Bachelor's degree programmes</b> in special needs education for disabled people.</p> <p><b>Provide teacher salaries</b> to NGOs which run educational and rehabilitation programmes</p>	<p>For advocacy related work, they co-ordinate with different departments within the Ministry of Education, e.g. curriculum development centre, teacher training institute and other technical centres for making each of these inclusive to the needs of the mentioned groups including the disabled children. They also co-ordinate with I/ NGOs and private educational institutions to make them disability-friendly and facilitate the district line agencies of education.</p>

Organisation	Objective	Target group and coverage	Programmes	Structure, partnerships, funding
Nepal Disabled Women's Association (NDWA)	<p>Established in 1997, they work for the rights of women living with disabilities and are operated by those same women. They have 19 district chapters and 2 regional offices. They have 21 staffs in total.</p> <p>The main <b>objective</b> of the organisation is to work for basic rights and empowerment of women with disabilities.</p>	<p>Their primary <b>target groups</b> are girls and women with disability. They also work with orphan girls who are disabled as well as with other people who work with disabled such as teachers.</p>	<p>They have the following <b>programmes</b> for disabled women and girls:</p> <p><b>National level advocacy</b> for implementation of existing policies, amendments on discriminatory laws, inclusion of disabled women in different organisations and helping women participate in relevant campaigns. They also conduct awareness raising on discrimination of disabled women, needs identification and assist disabled women access their rights and fight GBV.</p> <p><b>A rehabilitation centre</b> for disabled women and who have faced GBV and for disabled orphans (female) where they provide life-skills and livelihood trainings.</p> <p><b>Form village level self-aid groups</b> and carry out orientation, needs identification, training and engagement of disabled women.</p> <p><b>Promoting education for disabled girls</b>, orientation for teachers about Disability Inclusive Program (DAID), supervision and construction of assistive infrastructures such as service ramps in schools and public buildings.</p> <p><b>Provision of scholarships to disabled girls.</b> The amount is based on their resources</p>	<p>They mostly work with government organisations and other NGOs.</p> <p><b>Funders:</b> Their long term funding to run the rehabilitation centre comes from the government. Other funders include aid groups and individual project donors at district level including: Myride, Global Fund for Women (GWF), South Asian Women Fund (SAWF), American Joint World Society (AJWS), and OSF (Open Society Fund).</p>
Parent's Federation of disabled children	<p>Established under the Nepal Disabled Association by a group of parents with children with mental health conditions. They started by collecting a small amount of money amongst themselves and then with help from NFPU they were able to federate 26 similar institutions and finally establish a national level federation in 2011. They currently have 5 staff, a board of 13 members and a secretariat office. Currently they have networks in 46 districts.</p>	<p>Have networks in 46 districts. Target group are parents of children with mental health conditions.</p>	<p>Their <b>programmes</b> can be divided into 4 types: advocacy, capacity building, awareness and networking. They have largely focused on capacity building of member organisations and awareness-raising.</p>	<p>They were first funded by NFPU (Norwegian Association for Mentally Handicapped). Their other funding has come from Right Sweden, FFO Norway and Nepal Government.</p>





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