



Nepal's cash allowances for children with disabilities

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Key messages

- Children with disabilities continue to face discrimination and an uncertain future, despite progress in providing services to those living with disability.
- Among those receiving the disability cash allowance, many households saved this money for the future of the child with disabilities. Others spent it on meeting immediate needs, such as food, clothing, health and school expenses.
- Rates of exclusion from the disability allowance scheme are high, with estimates suggesting up to 60% of the eligible population may not be receiving the benefit.
- The barriers to accessing the disability allowance exist at many points of the application process, and include lack of knowledge of its existence, how and where to apply for the disability card, lack of appropriate documentation and challenges during the assessment phase.
- The disability allowance was one of five social security schemes to be scaled up as an emergency cash response in the earthquakes in 2015. Although few problems were reported in accessing the scheme in the earthquake, the current high exclusion errors limit the potential of using the scheme to respond to shocks in the near future.

Recommendations

- Raise awareness of and provide clear and simple communication about the disability card and allowance that is aligned to the assessment guidance.
- Review and improve the disability assessment process, including building up the technical skills needed to assess disability for the card.
- Consider automatically enrolling eligible disability card holders to receive the allowance.
- Ensure beneficiaries are able to apply for the disability allowance where they are currently residing.
- Ensure that infrastructure and services for delivering the allowance are accessible to people with disabilities.

Introduction

Nepal's disability allowance is one of five government-run social security allowance (SSA) schemes, 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 also entitles them to a number of discounts and services. To receive the disability allowance and to access specialised and/or subsidised services, people with disabilities need to hold a disability identity card, which categorises individuals according to the severity of their disability. Only those holding a red or a blue disability identity card (denoting 'complete' and 'severe' disabilities, per the government categorisation) are eligible to receive the allowance.

As of March 2017, almost 200,000 Nepali citizens held the disability identification card for 2016/17 (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) conducted the same year, estimated this to be even higher at 3.6% (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 (WHO, 2011).

The lack of standardised statistics on disability prevalence in Nepal means there are knowledge gaps. This is particularly concerning given the strong links between disability and poverty. Nepal is also particularly vulnerable to natural hazards such as earthquakes, floods, landslides and drought, and some research finds that people with disabilities often lack the resources to evacuate threatened areas and typically live in low-cost, low-quality housing that is more prone to damage or collapse (Peek and Stough, 2010). As such, natural hazard-related disasters may affect people with disabilities – and especially children with disabilities – disproportionately.

Given the country's vulnerability to natural hazards, 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. The disability allowance was one of five SSA schemes used to deliver an emergency cash top-up in earthquake-affected areas. However, disaggregated information about children living with disability as well as the impacts the earthquake may have had on them is not readily available, and this is a key challenge in identifying their needs and providing relevant assistance during emergencies.

This briefing note summarises findings from a research study that examined disability and the disability allowance scheme in Nepal (Holmes et al.,

2018, available at odi.org). The research focused on children with disabilities, specifically 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. It employed a mixed methods approach, combining: a desk review of relevant literature; a quantitative analysis of an existing dataset on individuals with disabilities across Nepal; and a qualitative analysis of primary data from interviews with children with disabilities, their caregivers and families, and key stakeholders at national and local levels in and around the Kathmandu Valley (Khokana town, and cities of Bhaktapur and Patan). Findings from the primary data collection are, therefore, particular to this area.

Experiences of children living with disability

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.

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

The interviews with children and their family members illustrate a wide range of experiences, emotions and challenges associated with disability.

Both children with disabilities and their caregivers raised concerns for the psychosocial wellbeing of girls and boys with disabilities – often with distinct gender dimensions. Caregivers were often more concerned about girls with disabilities, fearing that others would take advantage of them. There were also accounts of girls with disabilities experiencing sexual harassment and sexual violence, including rape. Another area of concern for 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 examining education opportunities for children with disabilities, a concerning pattern of high dropout 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 dropping out of school are 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 and 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.

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 and costly operations outside of Nepal) 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. While those who have disability cards receive a discount on medicines, those without cards have to pay the full amount.

Caregivers mentioned a number of different approaches to caring for children with disabilities, including sharing the responsibility between the two spouses, having other siblings contribute, and leaving their other children in their maternal homes or leaving their employment so that they can concentrate on caring for their child with disabilities.

The disability allowance

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.

IDI, mother of girl with epilepsy, Chakupat

People with disabilities who hold a red or blue disability card 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.¹ The money is transferred through the bank or hand-delivered every four months.

Recent studies have shown that the disability allowance positively contributes to the economic wellbeing and health of children (Roelen and Chettri, 2016). Our interview findings reinforce this: parents of children with disabilities who have a disability card and receive the allowance reported that they either save the money for their children's future 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 particularly important for children with disabilities

because they do not receive as many other social benefits compared with other disabled age groups.

The quantitative data analysis also revealed, however, that there is a high number of people living with disability who do not have a disability card (83%).² Moreover, exclusion rates among people who do hold a red or blue disability card but *do not* access the disability allowance are also high: between 30% and 60% of the eligible population (see Box 1).

Box 1 Exclusion errors from the disability card and allowance

While reliable data is difficult to obtain, secondary data and an analysis of a survey (2014 and 2015) on the living conditions among people with disability in Nepal (Eide et al., 2016) finds that across all individuals with disabilities (including children), 83% do not hold a disability card of any colour. Interestingly, further analysis 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.

There is also 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 individuals who are eligible for the disability allowance are not receiving it. Drawing on the analysis of the data from Eide et al. (2016) 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%).

1 Two other social security allowances provide Rs. 2,000 a month (the old age allowance, and scheme for endangered ethnicities); the widows allowance provides Rs 1,000 a month; and under-five grant provides Rs400 a month for up to two children per household.

2 This may be from choice (e.g. people voluntarily not applying for a disability card because of stigma) or because they face barriers in accessing the card.

The qualitative data explored the reasons for these barriers in accessing the allowance, and revealed that key challenges were:

- not knowing that the disability ID card or the allowance existed
- a lack of clear information on how to apply for the card, including on the eligibility criteria
- the difficulties obtaining the correct documentation to apply for the card (including citizenship documents)
- the difficulties associated with applying in their home village if they are living elsewhere, especially if this meant taking children out of school to apply
- challenges in the assessment phase, including lack of clarity on how the assessment guidelines are interpreted to assess disability, and concerns of corrupt practices
- lack of information on the requirement to submit documentation for the allowance after the receiving the disability card.

For example, a 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 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 area to file the application. In one case, where the child had to be present and return to the local area to apply, this was difficult due to being in school.

Some respondents were denied a card at the assessment phase. Key informants and some parents of children with disabilities identified the lack of clear guidelines and the complexity of assessing disability as problems at this stage of the process. For example, in instances where a child did not show signs of physical disability, there were reports of applicants 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.

For those who held a card, but did not receive the allowance, this was due to the additional administrative task of registering their names with the Village Development Committee (VDC)³ as there is no automatic link between receiving the card and receiving the allowance.

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).

Effects of the 2015 earthquake

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, Patan

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 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.

Very few 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 did not have any impact on the allowance – either in terms of issuance of payment or loss of their documentation. This was corroborated by key informant interviewees, 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 interviewee 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

3 Note that at the time of the study, VDC was the term used by respondents.

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.

Conclusions

While the disability allowance makes an important contribution to those who receive it – either as savings for the child’s future or to meet their immediate needs – the high exclusion rates from both the disability card and the allowance is of significant concern. Efforts must be made to overcome the exclusionary barriers if Nepal’s social security allowance system is to function effectively and if it is to be used to support emergency relief efforts in the context of future crises.

As such, we suggest a number of policy changes that are needed if the government of Nepal is to overcome these challenges:

1. Raise awareness of and provide clear and simple communication about the disability card and allowance that is aligned with the assessment guidance.

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. Review and improve the disability assessment process.

This includes increasing the technical skills and knowledge of committee members needed to assess disability for the disability card, organising more assessment camps, ensuring that people with disabilities can access the assessment committees, 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.

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. Ensure beneficiaries are able to apply for the disability allowance where they are currently residing.

Consideration should be given to simplify the application procedure to enable people who are not living in their original home locality to apply for the card and allowance, and therefore receive the allowance, where there are currently residing.

5. Ensure that infrastructure and services for delivering the allowance 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.

Service providers should explore opportunities to coordinate and link with other relevant programmes and services to address the challenges people with disabilities face.

7. Invest 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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This briefing note summarises a longer research report, which you can download from the ODI website (odi.org): Holmes, R., Samuels, F., Ghimire, A. and Thewissen, S. (2018) *Nepal's cash allowances for children with disabilities* London: ODI.



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