Include us in education!

A qualitative research study on barriers and enablers to education for children with disabilities in Nepal

Full report

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

International Centre for Evidence in Disability

Plan

Cover photo: Plan-sponsored girl smiling outside her family home, Nepal © Shubha Kayastha

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Introduction

Education has long been recognised as bringing a wide range of benefits and opportunities to individuals, their families and societies as a whole. While education is considered a right guaranteed to all children, children with disabilities face particular vulnerability to exclusion, and thus their participation in education often lags behind that of their peers. Denying children with disabilities the ability to exercise this fundamental human right not only propagates their continued marginalisation in society, but can also limit the potential economic, social and human development that can only be achieved with *universal* access to education.

While it is widely acknowledged that children with disabilities face exclusion in their efforts to access and receive an education, more research is needed to better understand *why* this disparity exists. Identifying the barriers – and enablers – to accessing education is vital to address these inequalities and ensuring that children with disabilities are able to exercise their right to inclusion. Furthermore, the quality of education children with disabilities experience is variable compared to that of their classmates; whilst not a focus of this research, accessing quality education is essential to ensure that children with disabilities have access to the same opportunities as their peers.

A previous analysis of Plan International's 2012 sponsorship data (Plan International and London School of Hygiene Tropical Medicine, 2013) revealed that across 30 countries, children with disabilities were on average ten times less likely to attend school than children without disabilities; children with communication or intellectual impairment were the least likely to attend school. When children with disabilities did attend school, their level of schooling was below that of their peers. They were also more likely to have reported a serious illness in the previous 12 months.

This report presents the findings of a **second phase** to the research; qualitative research was conducted to better understand *why* this disparity exists, and to identify the barriers and enablers to accessing education, focusing on the perspective of the child and caregiver. Nepal, one of the countries that participated in the original quantitative analysis, was selected for this study.

In-depth interviews were conducted with 21 families (20 caregivers and 13 children). All the children were in Plan's sponsorship dataset and had a range of reported disabilities. For further context, 19 key informant interviews were conducted and two special schools and one integrated school were visited.

Main findings

Children with disabilities are not attending, progressing through nor completing school for a number of complex reasons often involving a number of factors at individual, family, school and community levels.

At the time of the interviews, 12 of the 21 children were attending school, 8 children dropped out and one child never enrolled. Barriers to enrolling, staying in, regularly attending and completing school included:

- **Caregiver and teacher attitudes**, particularly if the child had an intellectual impairment.
- **Transportation** to and from school, which was a challenge for many children, particularly children with physical impairments.
- **Economic factors**, including indirect and direct costs of schooling, the opportunity costs of caregivers' time to take their children to and from school and the need for children to stay at home to work (both in the home and in paid labour).
- **Poor health** or the need for on-going **treatment and rehabilitation** that interfered with schooling.
- **Behaviour problems –** specifically amongst children with intellectual impairments who were often asked by teachers to leave the schools. Teachers reported being overwhelmed and felt the behaviour was distracting other students.

The research highlighted the negative psychosocial impact of dropping out of school. When children with disabilities stay at home all day, they have fewer opportunities to be with their peers, which further compounds their social exclusion. There were worryingly two reported suicide attempts by young girls who had recently dropped out of school.

Even when children with disabilities were enrolled in school, many faced difficulties that impacted on the quality of their education and their general well-being while at school:

- A third of the children with disabilities repeated a school year. It was also common for children with disabilities to be promoted up a grade without passing the current grade. Both of these are indicators that the learning of children with disabilities was not being adequately supported.
- Barriers to receiving a quality education included the **lack of specialist resources, adapted curriculum and teacher training**. This made it difficult for many children to learn, particularly in mainstream schools.
- Poor **physical accessibility** within schools could hamper the independence of children with physical impairments, particularly if they lacked assistive devices.

Violence, bullying and discrimination, by peers and teachers alike, were a pervasive experience in schools, as well as in community and home life. Overall two thirds of families (child and/or caregivers) reported bullying and violence in school.

Sexual violence perpetrated against children with disabilities also emerged as an issue and requires further research.

Both this qualitative research and the original quantitative analysis indicated that **children who have communication impairments**, such as a hearing, or some types of **intellectual impairments**, are particularly vulnerable to exclusion. These children often have trouble advocating for themselves - both at school and at home - and may have trouble learning if the curriculum, mode of instruction or teaching materials are not adapted.

While a few of the children in our sample had been to a special or integrated school, most caregivers expressed reservations about sending their child to this type of school. **Safety**, particularly for girls, was a major concern in sending children away for schooling. When children did attend such schools,

their segregation was perpetuated by the **lack of integration** with their peers without disabilities, as well as their families and communities.

Even in extremely challenging circumstances, most children wanted the opportunity to learn, to attend school and to be included with their peers. Enabling factors that helped children with disabilities in accessing and succeeding in school included:

- **Children's attitudes** towards school and **resilience** in the face of obstacles.
- **Caregivers who invest**ed in their child's **education,** doing the best they **could in often** difficult circumstances.
- **Supportive teachers and peers** who encouraged children and provided support when they could.
- **Plan Nepal and other NGOs played important roles in supporting** children with disabilities access education, such as by providing school supplies, information about different schooling options and other direct and indirect support.

Definitions

DISABILITY is an umbrella term for a person's impairments, activity limitations and participation restrictions and may refer to challenges they encounter in any or all of the following three areas:

- **IMPAIRMENTS** are problems in body function or alterations in body structure (e.g. hearing impairment, paralysis)
- **ACTIVITY LIMITATIONS** are difficulties in performing certain activities (e.g. walking, getting dressed)
- **PARTICIPATION RESTRICTIONS** are problems with involvement in life situations (e.g. exclusion from education, barriers to transportation)

SCHOOLING OPTIONS

- **INTEGRATED SCHOOLS** provide specialised instruction for children with disabilities in separate classrooms within mainstream schools. After receiving 2-3 years of training in these classes, children are expected to integrate into standard classrooms, where they are taught alongside children without disabilities.
- **SPECIAL SCHOOLS** offer specialised instruction in separate schools to children with specific types of disabilities. For example, children with profound hearing impairment may be taught in sign language at a special school for the hearing impaired.
- **MAINSTREAM SCHOOLS** do not offer any special support or resources to children with disabilities.

CAREGIVER: anyone in the household who is involved in the raising and/or daily care of a child. For this report, caregivers are mostly the children's parents, although in some cases they are their uncles, aunts, adult siblings or grandparents.

HEARING IMPAIRMENT: in this report this covers children who have a severe or profound hearing impairment.

Plan International has made ambitious commitments to the principle of inclusion and non-discrimination, notably in its Child Centred Community Development (CCCD) approach and its Global One Plan One Goal Strategy 2011-2015. Research such as this plays a pivotal role in ensuring that future programmes are developed using a strong evidence-base that articulates the complex challenges faced by children with disabilities and the opportunities that exist to address them.

(Aidan Leavy, Inclusion Specialist, Plan International)

Plan's sponsorship data is a unique and valuable resource that can be used for research purposes to inform Plan's programming. The first phase of analysis of the dataset which was conducted in 2013 highlighted important differences between sponsored children with and without disabilities. This follow-up research conducted in Nepal has helped explain why those differences exist, with important lessons learnt for programming.

(Jacqueline Gallinetti, Director of Research and Knowledge, Plan International)

1   Introduction

There are 150 million children with disabilities globally, many of whom face frequent barriers to their inclusion and participation in everyday activities (WHO and World Bank, 2011). While school enrolment may have increased for some types of impairments in a few low and middle income countries (LMICs), and some progress has been made with building the capacity of teachers in inclusive teaching practices, the overall quality of educational experiences for children with disabilities remains poor (Singal and R. Jeffery, 2011). Enabling these children to overcome such barriers is part of Plan International's commitment to the principles of inclusion and non-discrimination. It is central to Plan's child-centred community development (CCCD) approach that underscores all its work.

This commitment to inclusion was a key driver behind the research presented in this report. The first phase of the research was conducted in 2013 with an analysis of Plan International's sponsorship dataset across 30 countries (Plan International and London School of Hygiene Tropical Medicine, 2013). This showed that children with disabilities were on average 10 times less likely to attend school compared to children without a disability, and that when children with disabilities did attend school, their level of schooling was below that of their peers. The likelihood of being in school was related to the type of impairment, with children with vision and hearing impairments on average more likely to be enrolled than children with communication or intellectual impairments. Furthermore, the research showed that children with disabilities are more likely to have reported a serious illness in the last 12 months. These findings are important, but it was agreed that further qualitative research was needed.

This **second phase** of in-depth qualitative research used one of the 30 countries in the quantitative analysis, Nepal, as a case study to help identify possible solutions. Building on the strengths of mixed

methods of data collection, this research offers a useful model for other Plan countries of how to understand the situation of sponsored children and identify possible solutions.

Research aims and Objectives

The overall aim of this study was to explore barriers and enablers to education for sponsored children with disabilities in Plan Nepal as well as to demonstrate a research methodology that other Plan Country Offices can use to explore these barriers and enablers.

Specific objectives:

To identify the main barriers and enablers for sponsored children with disabilities to access education, from the perspective of the child and the primary caregiver.

To explore the school experience of children with disabilities, including the main barriers and enablers to their inclusion, progression through and completion of education, from the perspective of the child and caregiver.

To identify any particular challenges experienced around the transition from primary to secondary school.

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2   Policy and provision of education for children with disabilities in Nepal

Under Nepal's Interim Constitution, basic education (primary and lower secondary)[1] is to be provided free of charge to all children (Government of Nepal, 2007). As a partner in the Education for All (EFA) campaign, Nepal has committed to "meeting the learning needs of all children" and "ensuring that…all children, particularly girls, children in difficult circumstances and those belonging to ethnic minorities have access to, and complete, free and compulsory primary education of good quality" by 2015.

In line with the goals of EFA, the School Sector Reform Programme (SSRP) 2009-2015 was established to foster greater access, equality and quality of the education system (Ministry of Education of the Government of Nepal, 2009). To promote the inclusion of children with disabilities, SSRP mandates the creation of "enabling conditions in every school" and the expansion of disability-targeted scholarships (Ministry of Education of the Government of Nepal, 2009). The National Policy and Plan of Action on Disability (2006) then provides further support such as the extension of free education for children with disabilities, covering Early Childhood Education Development (ECED) through to higher education, and highlights the need to improve accessibility of the physical environment, learning materials and teaching methods (Government of Nepal, 2006). This policy also emphasises a shift in direction towards inclusive education (Government of Nepal, 2006).

As a model for inclusive education provision, integrated schools were piloted in 2006 and have now spread across the country as a means of increasing educational opportunities for children with disabilities (Barriga, 2011). In these schools, children with disabilities are taught in a separate classroom within a mainstream school for 2 to 3 years, with a focus on specialised training (e.g. sign

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[1] Nepal's education system is divided into primary (grades 1-5), lower secondary (grades 6-8), secondary (grades 9 & 10) and higher secondary (grades 11 & 12) levels. Additionally, the Early Childhood Education Development (ECED) programme provides preparation to young children before entering primary school.

language, Braille) and development of practical life skills. The goal is to then transfer children with disabilities into general classes, where they are taught alongside children without disabilities. Similarly, special schools also provide disability-specific instruction, however there is no expectation for children with disabilities to eventually integrate with children without disabilities. Finally, many children with disabilities attend mainstream schools, though additional support and resources are rarely available in these settings (Lamichhane, 2013, Barriga, 2011).

While there has been some scale-up in recent years, the capacity of special and integrated schools is still lagging (Lamichhane, 2013, Barriga, 2011). There are currently 365 integrated schools and 34 special schools for hearing impaired (n=19), intellectually impaired (n=14) and blind (n=1) children in Nepal. Given their limited geographical spread, most children must also board at school in order to attend.

While the Ministry of Education is responsible for the overall development of educational policies and programmes – with the Special Education Council dedicated to inclusive education provisions – implementation and oversight falls to the District Education Offices in each of Nepal's 75 districts (Barriga, 2011). The District Education Office works through resource centres, which are responsible for capacity-building of schools in the area. Resource centres are responsible for monitoring schools under their jurisdiction as well as organising trainings for teachers.

2.1   Children with disabilities and education in Nepal: current state of knowledge

Nepal has made strides in collecting more information on the situation of people with disabilities, yet official statistics vary widely. Based on conservative estimates of 1.63% prevalence of disability in 2001, there are at least 207,000 children with disabilities in Nepal (Barriga, 2011).

The Department of Education has also recently begun collecting information on the school status of children with disabilities. While these figures are useful, there is little information on the number of children with disabilities who are out of school.

Table 1 shows the enrolment of children with disabilities by school level:

Total enrolment	Primary	Lower Secondary	Secondary	Higher Secondary
Children with disabilities	48,575	16,401	6,760	2,248
All children	4,401,780	1,828,351	896,919	415,343
Percentage of enrolled children who have disabilities	1.1%	0.09%	0.08%	0.05%

Table 1: Number and percentage of children with disabilities enrolled in school; adapted from the Nepali Department of Education, 2013 (Ministry of Education of the Government of Nepal, 2014).

3   Methods

3.1   Study participants

The sample was drawn from Plan Nepal's 2012 dataset of sponsored children. Previous analysis identified 259 children with disabilities among Plan Nepal's 38,450 sponsored children (0.7% of sponsored children)(Plan International and London School of Hygiene Tropical Medicine, 2013). Disability was reported by caregivers during the annual questionnaire.

The 259 sponsored children with disabilities live across the six districts within which Plan Nepal works.[2] The districts of Morang, Sunsari and Makwanpur were selected for this study as together they comprise a mix of geographies (plains vs. hills areas) and could be visited within the timeframe of the study.

Children of school-going age (6-17 years) were selected to ensure that the sample was representative by impairment type (intellectual, physical, hearing and visual impairment), gender, age, district of residence and school status (in vs. out of school). The selection was carried out by researchers from the London School of Hygiene and Tropical Medicine (LSHTM) using datasheets with basic demographic information provided by Plan Nepal.

Key informants included government officials, members of Disabled Peoples' Organisations (DPOs), school teachers and Plan staff.

3.2 Ethical considerations

Ethical approval for this study was received from the LSHTM and the Nepal Health Research Council in August 2014. The research also adhered to Plan's child protection policy and guidelines. If child protection issues arose, Plan Nepal was notified of the situation and additional support and counselling for the families and sponsored child was made available.

Before the start of each interview, informed written consent was received from key informants, caregivers and older children. For younger children and children with communication/intellectual impairments, a simplified oral consent was sought, and pictorial child-friendly information sheets were developed. All names of children have been changed in order to maintain confidentiality.

3.3 Data Collection

Children and caregivers and were interviewed separately. However, if a child was unable to communicate independently or requested the presence of his/her caregiver, caregivers were invited to join the interview. Interviews were conducted in Nepali or the local dialect, with the support of a translator. For individuals who were profoundly hearing impaired, a sign language interpreter was available.[3]

In all cases, information about the communication abilities of the children were sought in advance of the interviews, both from Plan staff and the caregivers, in order to decide on the best approach for the interview.

A semi-structured questionnaire was used to guide discussions. Key topics covered in the caregiver interviews included:

- Family background
- Child's impairment, abilities, and general health, including access to health/rehabilitative services
- Child's education, including experience in school and/or reasons for non-attendance

Child interviews focused on positive and negative experiences at home and at school. A participatory tool called the 'Feeling Dice' (Messiou K, 2008, Morris et al., August 2005) was used to help prompt discussion and increase comfort levels with younger children (approximately 12 years and younger) and with older children who had an intellectual impairment. Each face of the dice had a different

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[2] The six districts comprise of: Banke, Makwanpur, Rautahat, Sindhuli, Sunsari, Morang
[3] Of the three profoundly hearing impaired children in the sample, only one was able to use sign language.

emotion drawn on it (happy/sad/angry) and with each throw, the child would be prompted to talk about this emotion in relation to their school and home experience.

For key informants, questions were tailored to each individual's area of expertise, but broadly focused on family/community, school and policy barriers and facilitators to education for children with disabilities.

All interviews were recorded and all caregiver interviews were transcribed. Children's interviews were more participatory in nature and sometimes involved the use of sign language, and therefore detailed notes were taken and cross-checked with the Nepali research assistant. Detailed notes were also taken of all key informant interviews, and where necessary, the notes and quotes were cross-checked against the recordings.

3.4   Data Analysis

A thematic approach was used to analyse findings. After each day of fieldwork, interview notes were reviewed by the lead LSHTM field researcher and the local research assistant. This helped to identify any gaps in the interview schedule that needed to be addressed and also provided some emergent themes. On the completion of field work, these emergent themes were shared and verified with a local reference group of young people with disabilities in Nepal[4] to obtain their feedback. Additionally, a second researcher at LSHTM read all the interview notes and transcripts, and a fuller framework of themes and sub-themes was developed, with additional sub-themes added during the data analysis process. Data was coded using NVivo 10, specialist software for qualitative data analysis.

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[4] National Disabled Youth Network.

4   Description of the sample

4.1   Caregiver/Children

A total of 21 families were visited, producing 20 caregiver and 13 child interviews.[5] In the six cases where no child was interviewed, five were due to communication impairments related to their disabilities and one was due to a child declining to participate.

Of the five children where communication impairments constrained the progression of the interview, four had severe intellectual impairments that limited their understanding and two were hearing impaired with no sign language knowledge.[6] In the time frame available for the interviews, it was not possible to spend more time with each child to effectively develop alternative modes of communication.

By gender, there were twice as many girls (14) as boys (7). This overrepresentation of girls is reflective of the total population of sponsored children with disabilities within the three districts visited (61% female overall vs. 66% in the sample). This also reflects the emphasis on girl's sponsorship within the Plan Nepal programme (74% girls and 26% boys according to 2012 sponsorship data).

CHARACTERISTIC	#
Gender	
Boys	7
Girls	14
School status	
In school	12
Out of school	9
- *Dropped out*	8
- *Never been*	1
Impairment type	
Multiple	9
- *Includes intellectual*	8
- *Includes physical*	6
- *Includes vision*	2
- *Includes hearing*	2
Physical (only)	5
Intellectual (only)	4
Vision (only)	1
Hearing (only)	2

Table 2: characteristics of study sample

By impairment types, the following breakdown was reported by carers: visual impairment (n=3), physical (n=11), intellectual/communication impairment (n=12) and hearing impairment (n=4; profound, n=3). These figures include nine children with multiple impairments. Most impairments could be characterised as moderate to severe. It should be noted that there was some discrepancy between impairment types recorded in the original Plan data received and those observed/reported by families during the interviews for this research. Notably, intellectual impairment was underreported in the Plan data, highlighting the need for more accurate methods for collecting of data on disability.

Twelve of the twenty-one children were currently attending school. Of the nine that were not in school, eight had dropped out and one had never attended school. Of all the children who had enrolled in school, all but one attended a mainstream school for at least part of their schooling. A further two had attended special schools and one had
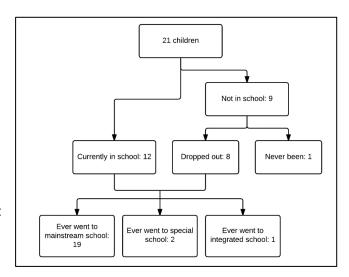

Figure 1: School status of children in the sample

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gone to an integrated school, all for short periods of time ranging from a few months to two years.

4.2   Key Informants

In total, nineteen key informant interviews and small group discussions were conducted: government officials (n=3), DPO leaders (n=4), Plan staff (n=3), teachers (n=6), students attending special schools for the hearing impaired who were not sponsored by Plan (n=2) and an academic expert in inclusive education in the UK. Two of the teachers provided information on the school experience of sponsored children from the sample. Additionally, school visits were made to two special schools for the hearing impaired and one integrated school for children with intellectual impairments.

5   Findings

5.1   Children who are not in school

Reasons for why children with disabilities may drop out of school are complex: as seen through this study, often a combination of individual, family, school or societal level factors were at play, with different weightings for every child. The additional influences of gender, poverty, caste, religion and other elements frequently worked in synergy with disability-related factors to compound or mitigate exclusion.

The range of challenges which led to children dropping out of school were the same as those experienced by children with disabilities who were still managing to stay in school. Often, these difficulties led to decreased attendance, difficulties with learning and negative experiences at school.

5.1.1   The lives of children who are not in school

Through following up with children with disabilities who are not in school, this research has thrown some light on the psychosocial impact of dropping out of school. Caregivers and children alike spoke of boredom, anger and frustration, and in some cases this had serious consequences.

One mother described how her daughter has learning and communication difficulties and kept on repeating the same class (grade 1), yet "she was very fond of learning. Even now, at home, she would get a notebook and pen and write on her own." The teachers asked her daughter not to return to school, and now she sometimes just sleeps all day. Her daughter smiles and laughs when she talks about her old school: "I miss reading and writing the most. I feel angry that I can't go back to school."

Another girl who dropped out of a special school for the children with hearing impairments talks about her sadness that she cannot return. "I feel like a donkey because I am just staying at home doing nothing all day." Her sense of frustration is further compounded by the fact that she cannot communicate with her own family with sign language, "people at home don't understand my language," and they also get angry with her "my mum gets mad at me because I can't understand her."

When the children are at home all day, there are fewer opportunities to be with peers, and this further compounds their isolation and social exclusion. Within our sample of twenty-one children, there were worryingly two reported suicide attempts by young girls who had recently dropped out of school.

Case Study: Impact of Dropping Out

Aisha is 12 years old and lives with her parents. She is the youngest of five children. She has a physical impairment, and has difficulties with mobility and balance, which means that she cannot walk long distances and falls down frequently. Her condition is getting worse. Her family has sought a considerable amount of medical treatment for her, although there still appears to be no clear diagnosis of her condition.

Aisha went to primary school regularly and did well. She liked going to school. However because of the longer distance to the secondary school she has stopped attending. Her father has tried to take her to school on his bicycle, but she falls off due to poor balance.

In the last couple of weeks Aisha has reportedly tried to commit suicide by drinking pesticides. Her mother explains how her daughter is sad about her condition, and "*she says herself that she can't go to school and she can't do any work, so she got frustrated.*"

Aisha says that she really wants to continue with school, and hoped to become a teacher "*I liked everything about that school,*" "*I feel sad that I can't go to school.*"

In the last couple of weeks she has started to go to some extra informal education classes, a couple of hours a day, provided by Plan Nepal. She does enjoy these, but still wants to go to secondary school with her friends.

The family are hoping for treatment to alleviate her condition and that a wheelchair might help her get to school.

Case 318 – perspectives from parents and child; all names have been changed to protect confidentiality.

5.2 Barriers affecting access to schools

Children with disabilities faced difficulties accessing or regularly attending school due to a combination of factors detailed below.

5.2.1 Caregiver and teacher attitudes

Many caregivers questioned whether their child could receive a meaningful education, even if their child was currently attending school. Caregivers, particularly those with children who had an intellectual impairment, questioned whether there was any use in sending their children to school. In some cases these attitudes were also mirrored by teachers.

[Why doesn't she go to school?] "She doesn't hear anything that's why…She is dumb, what should I say! I don't know if she would be able to learn."

<div align="center">Case 304: Mother talking about why her daughter, who has a hearing and intellectual impairment, has never been to school.</div>

In a small, but still important, number of cases, the child seemed far more capable than we were led to understand. Once a child is defined as "disabled", in particular if they have communication impairments, there is often an attitude that the child is not able to understand or do anything. In turn, caregivers and teachers tend to underestimate the ability children with intellectual impairments, including their capacity for learning:

[The community] "thinks children with disabilities are useless, a burden and don't realise their potential…teachers aren't willing to enrol children with disabilities, [so] when they try to enrol, they get discouraged."

<div align="center">Plan Nepal staff members discussing attitudes towards children with disabilities.</div>

5.2.2   Behavioural problems

In the cases where children with intellectual impairments exhibited behavioural challenges, all the children were out of school. In all cases, the school suggested or explicitly requested the child not be sent to school. Teachers often felt that the conduct of these children was disruptive to other students in the classroom. They sometimes felt overwhelmed, or that they did not have the capacity or resources to manage the children effectively.

"She just used to dance in school and she didn't attend the classes. Other children just used to come out of class to watch her… When I talked to the teachers, they said other children get distracted, so she should not be sent to school. I think it would be helpful if she could be sent to some special school or organisation.

[When you found out that Amita shows bad behaviour in school, was it you who decided not to send her to school or was it the teachers?] "The teachers said not to send her, so we can't do anything with that. And I think that she is disturbing others in school."

<div align="center">Case 303: Father explaining why his daughter, who has an intellectual impairment as well as a minor physical impairment, is not attending school.</div>

The capacity of teachers to manage children with behaviour problems, as well as their understanding and attitude about the child's impairment, appear to be important reasons for non-attendance and needs to be further explored.

5.2.3   Transportation to school

A third of families cited challenges in bringing their children to school as a reason for non-attendance or absenteeism. Most of these cases concerned children with mobility limitations, who struggled to travel to school due to their impairment:

"During the rainy days, she can't walk…she can't balance herself when the floor is wet. Sometimes she falls even if the floor is dry….she misses around 3 months of school in a year…We don't let her go to school during the rain…I am worried that if she falls and

something happens to her, others would blame me for not taking care of her, as she is not our own child."

Case 313: Aunt explaining why her niece, who has mobility limitations and an intellectual disability, doesn't attend school during the rainy season.

When children with significant mobility impairments were attending school, family members were often involved in their transport. In these instances, carers had to be able to physically support the child (e.g. carrying on their backs or on a bicycle) and take time out of their day to bring the child to and from school. Thus, if carers weren't available or able to help with transport, children would often miss school.

In one case, provision of an assistive device was suggested by a caregiver as a solution for overcoming challenges in getting to school. However, in other cases, children already had assistive devices such as wheelchairs or prosthetics, but because of the terrain, were still unable to travel independently to school.

5.2.4   Economic factors

Although under Nepal's Interim Constitution and other national policies, education is to be provided to all children free of cost, many families often still have to pay for uniforms, exams, stationary and other (small) fees for their children to attend school (e.g. school lunches, library fees, etc). For families living in extreme poverty, these fees may pose a substantial burden.

Disability scholarships are designed to provide financial assistance to help children with disabilities attend schools, particularly special and integrated schools which often also have boarding costs. Key informants familiar with the process note that when children are receiving these scholarships – which are paid to the school, not to families – direct costs of schooling are rarely an issue. However, to be eligible for a disability scholarship, children need to have a disability card, which can be difficult to obtain: families are required to attend a processing office in an urban centre (although community-based 1-day registration camps are becoming more common), with the child and have appropriate documentation (such as a birth certificate, and passport style photos). If administrators are unsure of whether an individual has a disability or what category their disability falls into, children are referred to a doctor for an assessment. This process can be arduous, particularly if families are on low incomes or living in rural areas without transportation links.

Plan Nepal has made strides in helping families overcome many of these direct costs of school, and in one district it was evident that Plan played a key role in facilitating the disability card application process for many families. As disability cards not only assist individuals and their families but also provide the government with data to better plan services, Plan's involvement in this area is highly beneficial.

When direct costs were mentioned as a barrier by families, most were referring to reasons for not sending their child to a special or integrated school. In these cases, lack of information seemed to be at play, as caregivers assumed these schools would cost money and thus did not pursue more information about these options.

Opportunity costs appear to be a more persistent barrier, notably; the cost of caregivers' time in bringing their children to school was mentioned frequently, as caregivers would often spend

significant portions of their day taking their children to and from school, resulting in missed time at work:

> "She couldn't continue her education because the transportation that was being provided by the school stopped... Now, as both me and my wife don't have much time out of our work, and she can't go on her own, it is difficult for us to drop her and fetch back from school every day…So, now her education stopped."
>
> Case 305: Father and mother explaining why their daughter, who has a profound hearing impairment, stopped attending a special school.

This challenge was also mentioned by caregivers whose children were currently in school but were dependent on them for transportation, and was reported as a cause for missed days of school.

Finally, in two cases, children with disabilities were kept out of school to work, both for work around the house, one for additional paid work outside. Another child was missing substantial amounts of school in order to work (for income) part-time. As this information was disclosed by children and not caregivers, it is possible that there was underreporting of being out of/missing school for work.

5.2.5   Poor health, treatment and rehabilitation

The original analysis of the sponsorship data indicated that children with disabilities were much more likely to have reported a serious illness in the last 12 months compared to children without a disability. This is consistent with the findings from this qualitative research.

Half of the caregivers reported that their child was more frequently ill compared to their siblings. In some cases caregivers described how their child had always been more susceptible to ill health from birth, with difficulties with eating, frequent stomach problems, diarrhoea and fevers as common complaints. Malnourishment and stunting was observed in several cases, possibly linked to the underlying condition. Due to the low socio-economic status of many families – with many households lacking adequate water and sanitation facilities – hygiene was often a concern, particularly for children with intellectual disabilities or mobility limitations. Caregivers also expressed how difficulties in communication sometimes made it more difficult for their child to explain their illness.

In addition to poorer general health, some caregivers were still seeking a 'cure' for the disability, with visits to various doctors and traditional healers. A number of children also required on-going treatment and rehabilitation. One mother described how they had attended various clinics, including going to India for a 'cure' for their child. Her son was more frequently ill than his brother with minor ailments, and they visited the local doctor four to five times a year, explaining that "he has difficulty with eating. He has a problem with his toilet habits because he doesn't understand."

Poor health clearly has an impact on children's education; some regularly missed school, fell ill during class time and had much longer periods off school, sometimes for several months, because of on-going treatment and rehabilitation. Time out of school for longer periods resulted in a couple of children having to repeat grades, which meant that they were no-longer with their peer group when they returned to school. One mother describes her daughter's frequent bouts of illness and how she regularly missed school:

[When Shirisha was in school, how did the illness impact her schooling?] "When she used to go to school, she would cry in the classroom because of pain. She can't communicate her problems [to others]…Even when she is ill she would go [to school]. When teachers found out she was not well, they would ask her to go back home and she would come back crying."

<div align="center">Case 302: mother of child with intellectual impairment and limited speech.</div>

Poor health is also likely to impact learning even when children are at school, although it was beyond the scope of this research to explore this in any depth.

5.3   Challenges faced in schools

This section details challenges experienced at school, which may have contributed towards dropping out or impacted upon receiving quality education and general well-being while at school.

5.3.1   Learning challenges

Although many children were physically present at school, it is questionable in many cases whether they were receiving a quality education. For children with intellectual impairments, most difficulties centred upon general understanding, while for children with visual or hearing impairments, learning challenges are due to inappropriate modes of instruction.

5.3.1.1   *Repeating grades and upgrading without passing*

Typically, enrolment rates and grade levels completed are used as benchmarks for gauging participation and equality in education. However, the experience of children in this study suggests that these indicators may poorly reflect whether children with disabilities are actually receiving a quality education even if they are attending school.

A third of the children had repeated at least one year of schooling. Additionally, there was a more hidden – and common – indicator that the learning of children with disabilities was not being adequately supported: children with disabilities were upgraded to higher grades without passing:

"She repeated three times second or third grade. She can't really take her exams properly so there isn't any proper grading. The teachers upgraded her along with her friends…She can't read and learn. [At first] the teachers thought it would help her to learn better if she would repeat the same grade, but now she is upgraded to another class [even though she didn't pass]."

<div align="center">Case 301: Mother discussing grade repetitions of her daughter, who has a mild visual impairment and an intellectual disability.</div>

5.3.1.2   *Lack of specialist resources, adapted curriculum and teacher training*

Caregivers of children who had a hearing or intellectual impairment often indicated that their children needed some type of special support in the classroom, though they didn't know exactly what improvements would help their child:

*[Is there any special attention, support for her in the school?] "*No, it's just a normal class, no special attention. Other children in the classroom are given work to do but she would just scribble on a piece of paper randomly…."

"She goes to a nearby primary school, but she doesn't understand anything. She sits there all day and returns."

Key informants were able to provide additional details on the system-wide challenges of educational provision for children with disabilities in mainstream schools. Lack of adapted learning materials in mainstream (and even integrated/special schools) was cited frequently as a barrier to providing a quality education to children:

"There's a lack of technology and appropriate learning materials such as Braille. Being deprived of these necessary materials puts teachers at a disadvantage as it's hard for them to do much even if they have the will to do so."

In addition to lack of adapted learning materials, the overall curriculum is not always designed to facilitate the teaching of children with different learning styles or abilities. This is particularly true of children with intellectual impairments, who may learn in different ways or at a different pace and thus benefit from an adapted curriculum.

Finally, teachers in mainstream schools receive minimal disability-specific training. As part of their general teacher's training, there is only very basic instruction on working with children with disabilities, such as to put children with visual impairments at the front of the class so they can see the blackboard. Teachers do not receive any compulsory training in working with children with more severe disabilities, perhaps under the assumption that these children will be funnelled into special and integrated schools. However, in looking just at the sample in this study, many children who have profound hearing impairments, complex learning needs or behavioural problems are being placed in mainstream classes where teachers have had very little to no training on how to teach and provide support to these children.

5.3.2 Physical accessibility

For children whose impairments severely restricted mobility, moving around school could be a challenge,[7] particularly if they did not have an assistive device. In contrast, when assistive devices were available for use at school, children had more independence:

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[7] Although 10 children with physical impairments had attended school, in most cases the impairment was minor or only affected walking longer distances (i.e. difficult to get to school, but once there, children were able to move around independently).

> "I don't have any trouble getting around school in my wheelchair…it is useful for getting to class, the bathroom. Otherwise I would need help to do these things."

> Case 308: Plan sponsored boy, who is a double amputee, explaining how he gets around at his secondary school.

Key informants also reinforced the difficulties surrounding physical accessibility in schools. They noted that the lack of disability-friendly infrastructure, such as ramps and toilet facilities, could impede access for children with physical impairments. Inaccessible washrooms were cited as a particular barrier for girls, where issues related to menstruation were raised as being of particular concern, as well as their safety if assistance was needed.

5.3.3   Communication barriers

Challenges with communication, for example, experienced mostly by children who have a hearing impairment or have certain types of intellectual impairments, appeared to frequently lead to difficulties in learning, as well as frustrations for teachers and child alike:

> "The teachers don't understand Kamala, and Kamala doesn't understand them. Even for us as parents it not easy to understand her language, for teachers it must be difficult."

> Case 315: Mother and father discussing their daughter, who has a hearing and visual impairment.

For children with communication impairments, the inability to express and advocate for themselves appeared to lead some teachers and caregivers to underestimate their abilities, believing that the child just "didn't understand anything", rather than recognising the need for alternative modes of communication.

5.3.4   Age-related issues

Due to late starts in school, gaps in schooling or frequent grade repetition, some children – namely children with intellectual impairments – were significantly older than their peers: for example, two adolescents with intellectual impairments were in early primary and nursery classes. In these instances, teachers felt it was inappropriate – and against Nepali educational policy – for these children to be in classes for young children. Furthermore, the advanced age presented additional challenges for care.

Additionally, being older than their classmates was cited by some children who had missed school as a reason for not wanting to attend:

> "I don't want to go back now…I don't think it would be useful…I've forgotten all I've learnt…I would be in grade 3, with just small kids …I would miss being with my friends."

> Case 307: Boy, with back problems that developed after leaving school, explaining why he does not want to return to the mainstream school he dropped out of three years ago.

The desire to be included with peers continually reoccurred as both a powerful motivator for wanting to attend school or, as illustrated here, a deterrent to return or continue if they were out of step with their friends.

5.4   Special and Integrated Schools

Only three children in this study had ever been to a special or integrated school, and all had since dropped out. Since we interviewed families in their homes, we ended up excluding children who may have been staying at a hostel, a common experience for children attending special and integrated schools in Nepal. However, as many families considered sending their child to one of these types of school, this research is able to highlight important barriers to enrolling children with disabilities in special or integrated schools. In addition to the experience of the children and families in our sample, one integrated school and two special schools were visited to provide more information on these schools.

Attending special and integrated schools could also be a positive experience for children. Inclusive approaches to communication, such as use of sign language can assist learning and help develop relationships:

Children at a special school for the hearing impaired during an assembly

"I was very happy when I went to the special school. Everyone could communicate with each other."

Case 305: Girl who has a profound hearing impairment reflecting on her time in a special school (via sign language interpreter).

Many caregivers were reluctant to send their children to special and integrated schools due to some of the challenges outlined below. Furthermore, key informants and the few children who did attend one of these types of school also brought up challenges associated with learning in these settings.

5.4.1   Challenges

5.4.1.1   Boarding situation, school environment and safety

As most districts only have a few special or integrated schools,[8] many children who attend these schools also board there. Sending their children away for school was an issue for many caregivers. They expressed that they would miss their child or that their child was too young to be living away from home. Additionally, safety and appropriate living situation while at school was a major concern, particularly for girls:

"There were only boys in the school, who teased her. In total there were six students and she was the only girl there…There weren't any girls so she might have felt alone. [Talking about the hostel]: They shared a single room…the caretaker sleeps in one bed and the children in one. *[Does Kamala tell you about anything she liked in school?]* No…she didn't like the school and always says she wants to stay home."

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[8] This is particularly true for higher grade levels: for example, there is only one special school for the hearing impaired that continues until grade 12.

Other safety issues mentioned included the lack of gates around school, so that "children wouldn't know where to play" or "someone could come in and do something to [the children]." Caregivers also worried that their child wouldn't be adequately cared for while staying at the school:

> The hostel was dirty, kids were hungry and there was not a good air. I heard that a child had died because of carelessness. I'm not interested in putting Aakash in this type of school.

In making decisions about sending children with disabilities to special or integrated schools, worries about safety and appropriate care appeared to outweigh the possibility of educational benefits. Many caregivers who were reluctant to send their child to board indicated that they would be more willing to consider options for special or integrated schools if their child could come home at the end of the school day. This issue highlights the need for suitable schooling options for children with disabilities within their communities.

5.4.1.2 Lack of resources

While integrated and special schools are designed to provide settings and resources that can support the learning needs of children with disabilities, key informants frequently spoke of shortfalls.

Public funding for special and integrated schools comes mostly from disability scholarships, which are disbursed directly to schools.[9] Teachers at these schools often felt that the amount provided was insufficient. In all three special and integrated schools that were visited, the school administrators spoke of needing substantial investments from NGOs, aid agencies and private donors to cover funding deficits. While these outside investments allowed these schools to improve their services, other special and integrated schools that aren't receiving this additional support may struggle to adequately provide for their students.

Additionally, while the availability of trainings to teachers has increased in recent years, key informants highlighted that teachers still often lack adequate skills to teach children with additional learning needs. Only resource teachers in integrated schools have a mandatory training, which consists of a one-off, 45-day long training for working with children with a specific type of disability. For learning sign language in particular, it is doubtful a month is sufficient time for most teachers to become proficient:

> "In the [integrated school] it was difficult to understand the teacher because he just used natural signs. He didn't have any [formal] sign language skills…maybe because he is old he couldn't learn sign language."

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[9] Values for special/integrated schools are: NPR. 5000/child/year if the child is not boarding; NPR. 30,000 (hills/mountains) or 25,000 (plains) if the child is boarding at the school.

Finally, key informants – including teachers themselves – felt integrated and special school teachers were not fairly compensated for their time. In a special school that was started privately and is now transitioning into the public system, teachers are paid well below the salaries of their counterparts in mainstream schools, which leads to low retention of staff. In integrated schools, resource teachers often work significantly longer hours than teachers in the other classes, but do not see that extra time reflected in their wages. Lack of fair compensation may thus disincentive working with children with disabilities.

5.4.1.3   Integration within and outside of schools

Although integrated schools are designed to be inclusive, segregation appeared to be still quite common. According to policy, children with disabilities are to receive a few years of specialised instruction in separate resource classrooms and then transition into general classes. However, according to key informants, this transition process is fraught with challenges.

A major barrier is that only the teacher in the resource classroom receives mandatory disability-specific training. While there is some expectation that they will pass on the information they have learnt to other teachers, there is no formal process or requirement to do so. While children who are visually impaired are better able to adapt so long as appropriate learning materials are provided, key informants note that children with hearing impairments in particular struggle to adjust as the teachers in the mainstream classes rarely have sufficient proficiency in sign language. For children with intellectual disabilities, key informants noted that in practice there has never been an expectation for transitioning to mainstream classes.

Integration outside the classroom was also noted by several key informants as an area in need of improvement, as playtime and school events were often separate. This concern was mirrored in the experience of the one child in the sample who attended an integrated school, whose father noted that children in the mainstream classes were in a different compound and didn't interact with his daughter.

Finally, key informants and some of the children who had attended special or integrated schools discussed challenges of reintegrating into their families and communities:

> "There's no parent training or involvement about their child's disability…When children go home over the holidays, they lose the skills we've been working on."
>
> Teacher in a resource classroom at an integrated school for children with intellectual impairments.

> "At home, people don't understand my language."
>
> Case 305: girl who has a profound hearing impairment and had previously attended a special school.

Although many caregivers had received recommendations from teachers, NGOs or DPOs to send their child to a special or integrated school, many felt they did not have enough information to make a decision, particularly if it involved sending their child to board:

> [Cousin]: "Once, an organisation came to take her to such a school, but they didn't send her. [Mother]: It was difficult to send her away. Also, we couldn't contact the people who wanted to bring her to that school because we don't have a phone. [Sister-in-law]: They [parents] didn't quite understand, more than they didn't want to send her away. They were uncertain where they would take her or what they would do. Rather than sending her away they kept her with themselves… [Mother] If they tell us about Amita's future, we would send her."
>
> Case 304: Mother, cousin and sister-in-law discussing the decision to not send sponsored girl, who has a hearing and intellectual impairment, to a special school.

5.5   Stigma, discrimination, violence and abuse in schools and the community

Stigma and discrimination are a pervasive theme across caregiver and child interviews. This is also reflected in the variety of derogatory and stigmatising terms which are used to describe the children; terms used by other community members, by teachers, and by other children. It is also used by some caregivers in describing their own children in their own home, sometimes with a view that their child cannot learn.

> "Call the dumb one (Latu le bulao)"
>
> Case 211 mother calling to her child to join the interview.

> "Other kids used to tease him. This one has no brain, so he would laugh and then they would beat him and he would fight back."
>
> Case 210: mother talking about her son, who has an intellectual impairment.

> Maiya is isolated in school, she sits on her own in a single bench, and her friends somehow discriminate [against] her."
>
> Case 201: Mother talking about her daughter, who has a mild visual impairment and an intellectual impairment.

> "Someone shouts at me and calls me 'cross-eyed' (deri) and pulls my hair." *[How many times has he said this to you?]* "Many times, 20 times."
>
> Case 306: Girl with a physical and intellectual impairment talking about bullying.

The stigma is also reflected in some of the life experiences of children and their families. Examples are a child being abandoned by her parents, or a father leaving after the birth of a disabled child, and of how children are excluded in the community by their peers. One common response is that some caregivers felt protective towards their child and so kept them at home. One mother here describes how her son, who is a double amputee, now stays mainly in the house:

> [*Does he have many friends*?] "Not many now. I don't allow him to go out much with his friends as he would drag himself to the playground and would hurt his knee… *[How does the community treat Bishal?]* Everybody discriminates against the disabled. People say we did some sin and that's why he was born like this. In the community, people use bad words so I ask him just to stay at home and not to go elsewhere…. His father actually left the house out

of shame because Bishal was born disabled. He hasn't even seen his son at all, it's been 14 years. They [community] also use bad words to like '*laangado*' and '*thudae*' (anyone who can't walk properly)."

5.5.1   Bullying, violence and abuse in schools

Bullying, abuse and violence emerge as a dominant theme; in the classroom, and on the journey to school. It affects all children with all types of impairments.

Overall two thirds of families (child and/or caregivers) reported bullying and violence in school. Caregivers always reported that their child with a disability was bullied more than their other children. Siblings and friends at the same school also confirmed the greater level of bullying and violence experienced by children with disabilities.

Both teachers and peers were commonly the perpetrators of abuse. In many cases children talked about one teacher who really helped them in the classroom and showed kindness to them, but they equally talked of other teachers who hit them because they were slower to learn, found it difficult to do an activity, or were not in a position to defend themselves against other children. Those with communication impairments appear to be particularly vulnerable as they may not be in a position to explain what is happening to them, either to teachers, or to their caregivers.

One girl of 12 years, with a visual impairment and intellectual impairment, describes how she feels sad at school because her "teachers and friends say I'm dumb and call me names…and I cry."

Another young girl of 17 years, who is profoundly hearing impaired, describes how happy she was at the school for the hearing impaired, but how she had a very difficult time at the local primary school: "I didn't like anything about school, I had no friends," while going on to explain her peers would lock her in a room and call her names and pull her hair. The teachers weren't much better: "There was one teacher, a fat one, who beat me the most, he beat me because I couldn't understand what he was saying."

Over half of the caregiver interviews also highlighted the bullying and abuse in schools.

"Usually her peers tease her for being mad, '*pagal*', and they get into fights for which teachers would hit Menkhu… Menkhu gets more of the beating compared to other children. That's why she doesn't like to go to school…Other kids in Menkhu's class bully her and get into fight with her, but instead they would complain to the teacher that Menkhu started the fight."

"His teacher used to beat him so he didn't want to go to the school*… [Did he have any friends in school?]* No he didn't have friends. He also didn't play with other children in the neighbourhood."

"We have to speak the truth. She isn't strong like us, she is disabled, so those who are able bodied show bad behaviour towards her. Only children from the family do not do this to her…She used to say a female teacher used to hit her but a male teacher likes her. She would say her friends hit me, pulled my hair and threw stone at me. But I don't understand her fully."

Case 302: Adult brother talking about his sister, who has an intellectual impairment.

5.5.2   Sexual violence

A real concern was that sexual violence and rape emerged as an aspect of community violence and discrimination perpetrated against girls with disabilities. As this topic wasn't probed during interviews, it is possible that sexual violence is underreported. One of the young people interviewed for the research was reported as having been recently raped by a neighbour. Her special school teacher explained that, in her experience, children with disabilities were especially vulnerable to rape: in her school of approximately thirty students (mixed sex), there have been three to four reported rape cases in the past five years. The view held was that children with communication impairments, such as those who have hearing or intellectual impairments, were at greater risk because they were not able to shout out whilst being violated, and/or had difficulty in communicating their experiences and advocating for themselves.

Case study on sexual violence

Roshni is a 17 year old girl who has a profound hearing impairment. She has recently been raped, whilst at home alone. After the rape she tried to commit suicide. Roshni's teacher at a special school for the hearing impaired explains that children with disabilities, especially children who have hearing or intellectual impairments, appear to be particularly targeted. *"These children cannot shout [out] and it's harder for them to communicate with others*."

Both Roshni's teacher and father comment on the poor attitude of the community towards the rape case. There is pressure from the community to settle 'out of court', less credibility given to the girl's statement, and more blame on the young girl, and a belief that the young person has been influenced. The response of the community highlights the prejudice and discrimination which clearly still exists towards disability.

While there can be stigma surrounding sexual violence for all victims, people with disabilities are particularly marginalised.

Roshni had to drop out of the school last year because her mother was ill, and she was needed to work at home. She really wants to return to school. Her father explains that *"she became future-oriented, she used to say she has to do something in future."*

Roshni is adept at sign language and is able to communicate at school with friends and teachers alike, whilst at home communication with family members is extremely limited. She says she is sad being at home and *"feels like a donkey"* sitting idly all day.

Case 305: Interview with father, daughter- via a sign language interpreter, and teacher. All names have been changed. Plan Nepal is aware of this child's situation and is working with the family to provide necessary support.

5.6 Transitions and the Future

Low transition rates to secondary and other higher levels of education were reported by key informants and some caregivers. As there are typically fewer options for secondary schools in general, children may face accessibility issues in reaching a new school further away from home:

> "Her school ends at 7th grade, so I'm not sure what she'll do after that. The secondary school is across the river and Jitendra can't bike."
>
> Case 313: Uncle of a girl with a physical impairment and intellectual impairment on challenges to progressing in school.

Additionally, special and integrated schools rarely offer grades beyond primary level. For example, in all of Nepal there are only three schools for the hearing impaired that go beyond lower secondary. Furthermore, government exams, such as that for the School Leaving Certificate, which is needed for advancement to higher secondary, may have accessibility issues, particularly for those who are blind.

Furthermore, caregivers and key informants often expressed concerns about whether the education provided to children with disabilities would adequately prepare them for independence and work in the future. Key informants emphasised the need to increase access to other forms of education – such as vocational and skills-based trainings - in conjunction with tackling work place discrimination, as a means for improving the transition from school to work for people with disabilities.

5.7 Enablers

What this research also highlights is the importance of children's personal factors; the resilience of many of the children and their determination to continue with their education, often in very difficult circumstances. In many cases caregivers want their children to go to school, and say that their children are eager to attend; children who have dropped out of school talk about wanting to return, and those in school want to continue.

5.7.1 Children's attitudes and resilience

Many caregivers talk about their child's enthusiasm for going to school, which is also mirrored in the children's interviews. Getting to school might be physically extremely difficult, they may be struggling to understand the teacher and to communicate, they might have to constantly repeat grades, and they may be bullied, and yet most of them still want to be able to continue with their education, and also want to meet with friends at school. The interview below with Bishal highlights the resilience seen in many of the children interviewed.

Case Study: Enablers

Bishal is 14 years old and is a double amputee. He is in the 8th grade of secondary school. He was helped by Plan to have operations on his legs and to get a set of new prosthetics. He lives with his mother and his sister, as his father left home immediately after his birth.

He drags himself around the house, and is carried to and from school by his sister. He used to be carried around in the village so that he could play with his friends, but in the last few years his mother discourages him from this as she is worried he will damage his knees. He does have a wheelchair at home but it is broken. He has been fitted with prosthetics, but, because he has recently lost a lot of weight they no-longer fit well and are painful to wear. He says the wheelchair is far more comfortable.

At school he does have a wheelchair, and this really helps him to get around. Bishal explains that when the wheelchair is being repaired, his friends will help him to get around the school.

Because of surgery last year he missed 3 months of school and failed his grade, and as a result he is having to repeat a grade. Normally he is incredibly motivated to attend school, and rarely misses school, even though getting to and from school can be difficult. He has even moved to live with his sister in order to attend a better school. His teachers have also been very supportive.

His mother tries to explain some of his motivation and determination:

> *[He seems to be a good student, what do you think has helped him to be like this and encouraged him to study?]* Bishal told me of a child who couldn't stand up and who has to lie down all the time. This child passed his School Leaving Certificate using his toes to write. So, he thinks he should now study more. He saw it on television. He says he should learn [to use] the computer but who would give him a computer? [*Has the school been supportive?*] I don't know how supportive, but they are nice. They like my son.

Bishal says that he wants to finish grade 10 and go onto higher education. He doesn't mind where he has to go to, as long as he can continue his studies. He would like to study computing.

Case 308: Child and parent. All names have been changed.

5.7.2 Caregiver attitudes

Although at times the research highlighted cases of neglect and discriminatory behaviour of caregivers towards their children, it is important to emphasise that a complex picture of home life was painted. Although there were some cases of neglect, some caregivers clearly wanted the best for their children, and were doing their best to support their children in often difficult circumstances, compounded by poverty, illness within the family, and sometimes the need to seek ongoing treatment and rehabilitation for their child. In some cases, other family members, such as siblings and aunts, were helping to take care of the child. Plan Nepal is giving extra support where required.

5.7.3 Supportive teachers

Although there is a strong theme of discrimination, bullying and abuse in the mainstream school environment, by both peers and teachers, it is also important to highlight that children often identified an individual teacher who encouraged and helped them. There were also examples of

teachers visiting the children's homes in order to encourage caregivers to let their children continue with schooling after the child had dropped out.

For example, one aunt describes the positives attitudes towards her niece:

> "She is happy with her teachers. They like Jitendra. If she is absent even a day at school, the teachers ask why she didn't come to school. People like her at school. She is quick in learning and reciting poems."

Case 213: Aunt talking about her niece, who has a physical impairment and an intellectual impairment.

Additionally, there were several cases in the special or integrated schools of teachers taking time and initiative – outside the purview of their job – to find private funding for required resources and support for their students with disabilities.

5.7.4   Role of peers

In a small, but important number of cases, other children play an important role in helping a child in school, or to get to school. For example, one boy with a physical impairment spoke of peers helping him move around school when his wheelchair isn't working. The support from peers is less apparent in the interviews with children with an intellectual impairment, and for some other children with communication impairments.

5.7.5   Role of Plan and other local NGOs

It was beyond the scope of this research to explore in any depth the role of Plan in the lives of these children, but in some instances it was clear that Plan had played a valuable role. All of the children are in communities sponsored by Plan and so would benefit directly or indirectly from projects and programmes operating in

Mother and daughter: Alina's family has been incredibly supportive of their daughter

their area. There are various instances where Plan played a significant role in helping the children to access health services, specifically for treatment of their impairment. In some instances Plan helped facilitate access to a vital assistive device, such as a wheelchair, or helped families obtain a disability card for their child. In one example with a child who dropped out of school, Plan set up 'alternative classes' in the community to help facilitate children returning to school. Plan, as well as other NGOs, has also played an important role in awareness-raising to caregivers on options for schooling, such as providing information about special schools, although insufficient information still appears to be a factor. There are also examples of small financial support for the education of a child, provided by a local NGO.

6   Limitations

First, it should be noted that as this study focused on children sponsored by Plan, their situation may not be representative of all children with disabilities in Nepal. These children may benefit from direct

or (more frequently) indirect/community support and thus may be receiving benefits not accessed by all children with disabilities. Alternatively, as Plan sponsored children are selected from amongst the most marginalised in a community, these children may face additional challenges not experienced by other children with disabilities.

Second, given the geographical diversity in area of residence and lack of exposure to formal education, some of the selected families did not speak Nepali. Therefore, a local Plan staff member was needed to assist in translation. Similarly, when children had severe communication problems, caregivers were often asked to help with interpretation. In both cases, the additional layer of translation, by potentially non-impartial individuals, may have resulted in the misinterpretation or misrepresentation of certain details; however, the independent research assistant/translator, who could partially understand many of the local languages, transcribed all caregiver and some child interviews in an effort to minimise these potential biases. The presence of the caregiver, and sometimes other family members may also have had an impact on what the child was willing to say about life at home and in school.

Finally, some children with intellectual impairments in the sample were not interviewed because of the severity of the challenges around understanding and communication, and in these instances information was generally provided by the caregiver alone. In the future, further approaches need to be identified to conduct research with children with intellectual impairments.

7 Discussion

Understanding the barriers – as well as enablers – that impact upon children with disabilities accessing and receiving a quality education is key for ensuring Nepal and other countries are fulfilling their commitment to promote the right of all children to education.

This research with Plan illustrates the importance of their sponsorship dataset, and of the value of mixed methods research: while the previous quantitative findings showed significant inequalities between children with and without disabilities in their attendance and progression through school, this study has provided some explanation for *why* those differences exist.

This qualitative research highlights that the reasons children with disabilities are not attending, progressing or completing their education are complex, involving a mixture of individual, family, school and community level factors. The variety of challenges expressed by key informants, children and their caregivers indicates the need for a more nuanced approach to education for children with disabilities. Providing a 'one size fits all' programmatic response for all children with disabilities, without addressing the interplay of all these drivers of exclusion, will prove ineffective in increasing access to a quality education.

Without a strong policy of inclusion combined with provision of specialised support, the opportunities for many children with disabilities to receive a quality education are limited. Even when children with disabilities were attending school, many experienced difficulties in learning due to reasons such as high absenteeism or lack of teacher training, specialist resources or adapted curriculum. Consequently, many were repeating grades, or more commonly, being upgraded without passing. These issues underscore that while indicators such as enrolment and grade levels are useful, it is essential to explore the broader picture behind the numbers.

While special and integrated schools may offer additional capacity to support the learning of students with disabilities compared to mainstream schools, their limited geographical spread means

children often must leave their communities to attend. The interviews illustrated why many caregivers were reluctant to send their child away to school and their willingness to consider options for special or integrated schools if their child could come home at the end of the school day. This issue suggests the need for suitable schooling options for children with disabilities within the communities in which they live.

In addition to focusing on improving school attendance and academic performance, this research also underlines the need to address the social experience of children at school, as bullying, discrimination and violence were all-too-common themes throughout the interviews. Sexual violence emerged as an issue of real concern, which requires further research. Furthermore, besides potentially limiting some of the economic and social benefits that are linked to increased levels of education, this research has thrown some light on the psychosocial impact of dropping out of school, and the additional vulnerability of these children.

Without the inclusion of children with disabilities, the promises of universal education will fall short. Investing in and engaging with schools and communities so that they can better provide a meaningful education and positive, inclusive school experience will benefit all children, with and without disabilities.

8   The Way Forward: Recommendations

The recommendations outlined below are the product of consultation with Plan staff and the Plan Disability Working Group. They build on both the first phase of the analysis of the child sponsorship data (Plan International and London School of Hygiene Tropical Medicine, 2013), as well as the in-depth qualitative work presented here.

8.1   Recommendations for Plan

- The first phase of the research recommended that Plan staff maximise the utilisation of the child sponsorship data to help identify issues that require further investigation and research about the lives of children with disabilities and to ensure that the findings inform decision-making. This has been acted on in a number of instances, e.g. monitoring, evaluation and research reports and management responses to research. The findings from this study indicate that this should continue.
- For disability to be mainstreamed into all programmes, for example, by ensuring that children with disabilities are part of the programme design and to include disability indicators into monitoring and evaluation frameworks for any new programmes. This would require Plan to consistently disaggregate data by disability and type of disability when collecting data.
- The first phase of the research recommended the improvement of training for staff who collect and analyse sponsorship data to improve the quality of the data and thus improve its utility. This is currently being implemented within Plan, and should continue: it is recommended that this be an on-going exercise to ensure continuing professional development.
- Provide training to all staff on disability and how to engage with children with different types of impairments.

- For a management response from Plan Nepal to be put in place in response to the findings; for example, in giving extra support to families where this was identified as a need.

8.2   Recommendations for communities and schools

- Conduct awareness-raising at the family and community level about the rights of children with disabilities in order to address many of the attitudinal barriers to education which exist.
- Promote 'healthier schools' which support the participation and inclusion of children with disabilities in all school activities, both in and out of the classroom. This can include a wide range of measures, such as those to improve safety, physical accessibility, inclusive water and sanitation facilities, stigma and bullying.
- Advocate for and put measures in place to increase the capacity of all schools to provide inclusive, quality education so that children with disabilities can learn in the communities in which they live and obtain a quality education. Specific areas for improvement include facilities, resources and teacher training, as well as measures for addressing bullying and discrimination, in order to support full participation of children in and out of the classroom.
- Combat stigma, abuse and violence perpetrated against children with disabilities. Furthermore develop and test interventions to reduce violence.
- Improve access to health and rehabilitative services, including provision of assistive devices, to improve overall well-being and independence of children with disabilities. Their health needs must be addressed in order to achieve improved educational outcomes.

Recommendations for governments

- Develop long-term, holistic and well-resourced action plans to address the material, cultural, physical, and attitudinal barriers that prevent disabled children accessing and completing a quality education. This should include targeted action plans to reduce stigma, abuse and violence perpetrated against children with disabilities.
- Develop curricula that promote inclusion and rights of disabled children, ensuring that education materials are free from discrimination and stereotypes of all kinds.
- Long travelling distances and a lack of accessible infrastructure to get to school can act as a disincentive for disabled children. Investments must be made in ensuring that school infrastructure is accessible to all, including disabled children.
- Improve access to health and rehabilitative services, including provision of assistive devices, to improve overall well-being and independence of children with disabilities. Their health needs must be addressed in order to achieve improved educational outcomes.
- Ensure that disabled children are able to participate in the design, implementation and monitoring of education interventions, including through the provision of accessible information, assistive devices, communication aids and interpreters.
- Provide sensitisation to parents and education professionals to strengthen their awareness of the obligation to provide inclusive education and to support children with disabilities to meaningfully participate in decisions that affect them.

8.3   Recommendations for Research

- Ensure that all research includes appropriate methods and budgets for involving children with disabilities, including those with communication challenges.

- Explore further the issue of violence against children with disabilities, including sexual violence.
- Explore further the issue of malnutrition, severe health issues and children with disabilities, given the findings from both phases of the research.
- Conduct research on the specific needs of children with intellectual impairments and their families, in order to identify the most suitable responses.
- Conduct longitudinal research with children with disabilities in order to improve understanding of the longer term outcomes for this vulnerable group, and thereby identify areas for improved disability-inclusive programming.

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