International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Strengthening the Voices of Adolescents with Disabilities in Nepal

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PLAN INTERNATIONAL

Research Team and Authors: Chet Raj Bhatta, Samjhana Bhujel, Sunil Dhakal, Navina Gyawali, Muniya K Shah, Shisam Shrestha, Anita Sigdel, Momsara Sunar, Sarah Bernays, Shaffa Hameed, Shubha Kayastha, Pragya Lamsal, Meenraj Panthee, and Maria Zuurmond

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Photo Front page: Focus group discussion in sign language with girls who are deaf

Photo: Focus Group Discussion with Girls group

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EXECUTIVE SUMMARY

The main aim of the research project was to understand what was important for the well-being of adolescents with disabilities (AWD) in Nepal. We wanted to understand what was important for them to have a ‘good life’ and factors which shaped their lives.

A second aim was to train a team of youth researchers with disabilities to help conduct the research. We wanted to better understand how to ensure people with disabilities were at the heart of the research, embracing the principle of ‘nothing about us without us’, and for the research to be youth-focussed and participatory.

We talked to a total of 52 young people 14-19 years old across four districts in Nepal; we conducted in-depth interviews with 26 young people and ran three participatory workshops with an additional 26 young people. We also talked to 12 ‘key informants’, such as parents and teachers.

Some of the key findings include:

Photo: Adolescent girl explaining her key issues using sign language at participatory workshop

- A **supportive family** is extremely important for AWD. Many feel loved and cared for by their family.
- Families are also complex. For some young people there is a **communication gap,** especially for young people who are deaf. Deaf young people commonly cannot communicate with anyone in the family, which can be extremely difficult. A small group of some AWD did feel there was no support and understanding of their situation.
- **Education** is considered vital for a good life, and this needs to be good quality education.
- Many AWD describe a difficulty in **transitioning to secondary school.** A particular challenge was the greater distances to travel, compared to attending a local primary school, with little or no access to suitable assistive devices which could alleviate this.
- **The physical environment** of schools and hostels can be inaccessible, especially for the visually and physically impaired, and in some cases, it can be very unsafe, which needs to be urgently addressed. The gap in accessible WASH facilities is a particular concern for adolescent girls in both home and hostel settings
- Many AWD usually had one teacher who particularly helped them, but **poor-quality teaching and limited educational resources** to support their learning needs, such as having materials in large font or audio books, or good visual materials (for the deaf), were a recurring in theme for at least half of those interviewed.

- Young people really want to play with their friends and keep active for a healthy life. In practice, **sports activities in schools are not inclusive**, or little or no sports is provided to them, even in special school settings.

- Many AWD have health and rehabilitation needs and economic factors are a key reason for not accessing services. Access to assistive devices appears very limited, with young people with ill-fitting equipment.

- There are substantial **emotional health needs** (psycho-social) **of AWD** which are not being addressed. This includes AWD feeling depressed, and in some cases suicidal, about their situations. This can be because of concerns about their health and treatment (or lack of), experiences of exclusion and being stigmatised, worry about their future. Although many AWD show resilience, it is also common for them to say they have no-one to talk to, or they not want to burden others with their needs.

- AWD aspire to work and have a good job, but the **transition to the workplace** and for gaining a livelihood is unclear to them. There are limited higher education or skills training courses available, and their own awareness about job possibilities is low. The quality of some of the school-based vocational training is seen as poor and not sufficiently inclusive of their learning needs.

- AWD identify **friendship as key to their well-being**. In their community there were important friendships that also help participation in community activities. However, lack of participation is equally common with at least one third of the AWD rarely leaving their homes to go out in the community.

- Overall, the AWD were very isolated, with limited support networks, and very few are affiliated to local organisations. This seemed to be most acute for AWD who have dropped out of school or college. It is also an issue for those who live away in hostels (a common issue for AWD) and then return to their home communities where support networks have not been established.

- Adolescent girls are more likely to describe being fearful about their safety if they go outside out of their house or their hostel on their own.

- Administrative difficulties were commonly experienced in obtaining a disability card, which commonly lead to many delays in accessing a variety of benefits, including financial support.

- Disability can seen as a ‘homogenous issue’ – one size fits all! Yet needs can be very different across the different impairment groups, and that is not always understood.

- The youth research associates were empowered by their participation in the research; increased knowledge, confidence in their new skills and they played a strong role in the analysis. There were considerable emotional demands upon them, and this requires support.

1 Background- why conduct this research?

The Global Strategy for Women’s, Children’s and Adolescents’ health focuses on ‘*Survive, Thrive and Transform*’ and yet there is limited research with adolescents to inform how this strategy can be implemented [4]. The Global Sustainable Development Goals [5] pledge that ‘*No-one will be left behind*”, and that children and young people with disabilities are the one of the groups most likely to be left behind.

The new Global Accelerated Action for the Health of Adolescents (AA-HA!) also indicates that adolescents with disabilities are a key marginal group [6] and that there is a need for a richer understanding of the life course of adolescents with disabilities; from childhood through to transitions into adulthood.

We know that the teenage years are a critical window when young people and caregivers develop their plans and expectations for the future [7, 8]. Adolescence is a vulnerable time for children and young people, with important transitions taking place – from primary to secondary school, from school to the workplace, and in terms of young people's relationships and sexual and reproductive health needs and right. We know from research in high income settings, that periods of transitions are also a vulnerable time for adolescents with disabilities [9, 10]. Research conducted by the International Centre of Evidence in Disability highlighted the particular challenges faced by children and adolescents with disabilities in accessing school and health services, and child protection services [11-13]. However, there are few studies that look at the specific needs of adolescents with disabilities, and this research project seeks to address that gap in the context of Nepal.

Photo: Voting on priorities, Adolescent girls, Biratnagar

Our use of terminology

Throughout this report we use the term adolescents and young people interchangeably in reference to young people who are 14-19 years. Our focus is on older adolescents and young people. We also use the term adolescents with disabilities (AWD) to include young people who are deaf.

Adolescence

'Adolescence' is formally defined by the UN as the period between 10-19 years, and 'Youth' is between 15-24 years. In practice, it is generally agreed that the definition of adolescence will vary across culture and context however we use this term to denote an age group of young people going through considerable physical, social and emotional transition [1, 2]. It is an important life phase between childhood and adulthood, and if given the right opportunities adolescents and young adults *'can transform all our futures'* [3]

2 Inclusive participatory research

2.1 Young people with disabilities as co-researchers

In this research, we wanted to embrace and operationalise the concept of '*nothing about us without us*' adopting a rights-based approach which involves young people with disabilities in all aspects of the research process. In practice, disability research rarely involves people with disabilities [14, 15], and is even less likely to involve children and young people with disabilities [16]. Our decision to have voices of adolescents with disabilities at the heart of the research was underpinned by the following rationale:

- For the research to embrace a rights-based approach, aligned with the principles of the Rights of Persons with Disabilities enshrined in the UNCRPD (UN charter on the Rights of Persons with Disabilities, and of the Rights of the Child enshrined in the UNCRC (UN Charter on the Rights if the Child) [17, 18].
- Young people with disabilities have the greatest personal knowledge of the issues, and accessing their particular knowledge can help in many ways, such as helping shape the research questions, in developing suitable and creative research tools, and conducting the interviews, analysis, and dissemination.
- Working with youth researchers can help to reduce the power imbalance that is often present between researchers and participants, and also between young people and adults. Young participants usually feel more comfortable if a young person like them is doing the interviewing and this allows rapport to be built quickly. It also builds credibility for the study among the participants [19, 20].
- Children and young people with disabilities are sometimes 'invisible' and it can be assumed they have nothing to say. Participatory approaches let them tell their stories and also to shape how their stories are told [16, 21].

Photo: Discussing what is meant by 'wellbeing', led by YRA

2.2 Adolescents with disabilities in Nepal

Current estimates of prevalence of disability vary, with the National Population Census of 2011 estimating 1.94%, while the National Living Standard Survey Report 2011 found a slightly higher prevalence of 3.6% [22]. However, both are low when compared to the 15% disability prevalence figure measured by the World Health Organisation and the World Bank in the World Report on Disability [23].

There is a growing body of research in Nepal on different aspects of sexual and reproductive health in adolescents and young people [24-27] and specifically around early child marriage, but little of this data looks at the specific needs of adolescents with disabilities. A national survey found approximately two-thirds of children with disabilities were attending school in comparison to over 95% of children without disabilities [28].

3 Aim and objectives

The overall aim of this study is to provide much needed knowledge about the well-being of adolescents with disabilities in Nepal and their needs and priorities.

3.1 Research objectives:

- To identify key factors which impact upon the well-being of adolescents with disabilities in Nepal
- To explore the contribution of peer-focused research with adolescents with disabilities

4 Research Methods

This was a qualitative research project, combining in-depth interviews and focus group discussions, using participatory tools. In total 26 interviews were conducted with adolescents aged between 14-19 years. They lasted approximately 1 hour and were conducted in the home or in school settings. Three participatory workshops were conducted in school settings; one in a special school for the deaf, and two conducted in inclusive school and hostel settings. In these workshops, space was given for single sex groups to work on their own. In addition, 12 interviews were conducted with key informants, mainly caregivers, to provide additional contextual information. All families were contacted in advance to check any communication needs of the adolescent. In two cases, the interview was with the caregiver, instead of the adolescent, because of communication barriers.

4.1 Participatory research with young people with disabilities

We incorporated youth voices as co-researchers into the different stages of the study. A group of Youth Research Associates (YRAs), who themselves had a range of sensory or physical impairments, were trained. They worked in collaboration with two experienced qualitative researchers (one national, one international). Our team of seven YRAs (22-26 years, five young women and two men) received an initial six days of training to develop skills that included basic concepts on qualitative research, techniques for conducting interviews and focus groups, issues related to working with young people, and ethical issues in research. This was followed by mentoring in the field by an experienced Nepali qualitative researcher.

Photo: Participatory workshop lead by Youth Research Associate

YRAs ‘buddied up’ (they worked in pairs) in the field, and took on a variety of different research roles, dependent on their skills and experience. Youth Researcher Associates were also asked to record daily reflections on their experience in conducting research, and to present key aspects at the final participatory analysis workshop. Their roles included:

- Feedback on the research questions, design and research tools
- Co-facilitation of interviews and focus group discussions
- Leading on interviews and focus group discussion
- Key informants about the local context (providing valuable information about the local setting) and supporting logistics
- Support with the analysis and interpretation

4.2 Participatory research tools

A mix of participatory tools was used for the training of YRAs and for conducting fieldwork. The rationale for using participatory tools is manifold; it would allow for a flexible approach to engaging with young people with a wide range of impairments and differing communication needs, to help build rapport, to make the interviews more attractive to young people, and to offer alternatives to only verbal discussions. The tools used for the interviews and mini-participatory workshops included: (1) the 'Ladder of life' - a visual tool with a diagram of a ladder with '1' being 'the 'worst life' and '9' being 'the best life'; (2) emotion cards and the 'Feeling Dice' to help illicit discussions about feelings (3) voting and sorting activities to stimulate sharing of ideas about their priorities, and (4) the use of photos to stimulate discussion about lives in different settings ('photo-elicitation') (5) collage was used during the training of the RYAs to explore their experiences of living with a disability[29-31]

Photo: Voting on priorities, Adolescent boys, Biratnagar

5 Study location and participant selection

Field work was conducted between August-November 2017 in four districts: Sindhupalchowk, Kavre, Magdhi and Biratnagar. These sites were selected so that there was a mix of urban and rural sites, and where both CBM and Plan International Nepal had programmes. The selection was made from a database or list of names provided by the local programme staff and from Disabled People's Organisations (DPOs). Criteria for selection of adolescents included a gender balance, adolescents living with different sensory and/or physical impairments, and a mix of young people who were in and out of school/college. Adolescents with intellectual disabilities were excluded because it was felt this would require the YRAs to have more experience, and to include additional interviews with family members, which were beyond the scope of this project.

5.1 Ethics

Ethical approval was obtained the Nepal Health Research Council (NHRC), and LSHTM. Full informed consent was obtained for all those who participated and for adolescents under 18 years, we also sought consent from a parent or guardian. Information sheets were available in an easy-to-read format, including a larger font version, and read to participants. The child protection policy was adhered to for both Plan and CBM.

5.2 Data Analysis

Overall a 'thematic analysis' was conducted (this is where you look in detail at the key 'topics' in the interviews and discussions). A two-day participatory data analysis workshop was conducted with the YRAs on completion of the fieldwork, to bring in their perspective on the key emerging issues. All the interviews were translated and transcribed from Nepali to English, and workshop was filmed and transcribed in English. The international consultant conducted a separate thematic analysis, using the coding tree developed at the workshop, with further sharing and discussion of key themes and sub-themes with the local researcher. This data was managed using NVivo 11.

6 Findings

We interviewed a total of 52 young people aged 14-19 years, 25 boys and 27 girls, with a range of sensory, physical impairments or multiple disabilities; 26 one-to-one interviews and three participatory workshops with a total of 26 young people.

6.1 Well-being in the home

Families are important to young people and **good family support** is considered crucial to have a good life. The majority, even those living away in school hostels, felt that they were supported and loved, and that parents provided the support they could.

However, the family environment is a complex one, and was not without challenges. These included a home environment that was often not physically accessible, a communication gap between parents and adolescents, limited independence, and stigma and discrimination. Poor economic conditions of families also exacerbated the difficulties experienced by the adolescents, and this was most notable in homes affected by the earthquake, where families where still living in makeshift homes. For AWD living in Kavre and Sindalpauchuk they were mainly living in temporary accommodation, and this resulted in particular challenges around access, especially in relation to water, sanitation and hygiene (WASH). It was fairly common for AWD to describe rarely leaving the house, with limited participation in the community.

6.1.1 A COMMUNICATION GAP WITH FAMILY MEMBERS

Photo: Girls only group, deaf school, Biratnagar

A **communication gap** with their families was a major theme across every interview with young people who are deaf, and was a major reason given for why life could be difficult at home, why they had difficulties in communicating about their health, and often resulted in them feeling isolated. All deaf people interviewed were living in hostels, often only returning home for brief periods 2-3 times a year. Parents did not understand any sign language, and where parents were illiterate then young people could not even express themselves through writing, spending time at home with no communication, only 'natural sign language' for the most basic of needs. Although many still said they wanted to go home, *"I feel I want to go home, even though no-one understands me"*, it was a key priority that parents should be offered something to improve communication:

> My mum is illiterate, so she also can't read, so when I go home I just keep quiet… (Adolescent girl, Focus Group Discussion, Biratnagar)

> In my family I have problem communicating, because of difficulty in communication we face lots of difficulty. (Adolescent boy who is deaf, 17 years, at a special school)

For those living in hostels, and returning home for only short periods of time only, there were examples of how parents were not always able to understand the issues that they faced when they returned home. Young people themselves did not want to share their problems, preferring to not share with anyone:

> I never tell my things to my parents. I never tell my things to anyone. I don't even share it with my friends. Only because you are asking that is why I am telling you otherwise I don't share my things with anyone. (Young man of 16 years with a physical disability)

6.1.2 PARENTAL UNDERSTANDING AND ATTITUDES

Although many of the young people interviewed were currently in school (17 of 26 young people in school), there were cases where AWD had dropped out of school and were at home, usually with no form of employment, and commonly felt misunderstood and/or excluded in the family.

In the case of a young deaf man aged 18 years old who had dropped out of school in class 6 (~ 10-12 years), and described how unhappy he was with life, whilst his siblings studied:

> At home, how is your life?
>
> It is not that good. It is difficult with my parents as they haven't learnt sign language and I have to communicate with them only in natural sign language……… I communicate with them by writing. Can you meet my parents and tell them that they need to learn sign language, and also suggest them that they should not discriminate those with disabilities?
>
> What should we tell your parents?
>
> I want to study. That is why if you can tell them that they must send me to school and education is very important (B24, Adolescent boy who is deaf)

It was not uncommon for young people to describe that they rarely left their home, one reason for which was parental concern for their safety, illustrated by the case of a young deaf woman who described feeling very sad because she hadn't been able to continue with her studies on completion of the school leaving certificate, and spent all her time at home. In the three months since leaving school she had rarely left the house; explained partly because she was Muslim which made it unacceptable for her to be out unaccompanied, and partly because her parents were fearful that something would happen because she was deaf. She saw little hope for future opportunities.

A very common theme amongst parents was great anxiety about their child's future, assuming their child would not be able to take care of themselves or earn a living, ''*I am worried that after we are gone, who will take care of him, where will he go...? These things bother me*.' Here a father is tearful about his 18-year old daughter who has had one leg amputated and has dropped out of school, whilst still living in temporary shelter following the earthquake:'*Her future is dark'…what can she do? She has no education."*

6.2 Well-being in schools and colleges

Access to a **good quality education** was the singular most important issue that adolescents prioritized as **necessary for a good life**. It was seen as the gateway to the future, and essential for gaining work, for improving their confidence, and gaining independence.

> What else would make your life fulfilling?
>
> I think if I could study, I would be really happy. I do not need anything else, I just want to study. (19 year old young woman with Polio)
>
> I think if one is educated, the he can live a happy and good life. Education makes us independent. Like, my parents will grow old soon, so I need to study hard now, be independent, and support my family. (Adolescent boy with a physical disability, 15 years, S 15)

In practice, their experience in school was varied, and there were many concerns voiced about the quality of their educational experience.

6.2.1 TEACHING QUALITY AND MATERIALS

Many young people identified individual teachers who were helpful, taught well, and gave them extra support as needed. However poor-quality teaching and poor educational resources, were recurring themes in half of the interviews, and across all three focus groups. This was most common amongst adolescent who were visually impaired or deaf. Teachers who had poor sign language skills was a common complaint; *'I cannot understand what the teachers are teaching, and that makes me unhappy' (K2)*.

It was commonly felt that there was a lack of understanding of their specific learning needs, and not making often simple adaptations to the lessons to meet those needs. For example, young people with visual impairment in inclusive school settings described difficulties when teachers did not dictate whilst writing on the board, which meant they could not access the lessons unless supported by their peers. There were also requests for more teachers to able to use Braille in inclusive school settings.

> I wish that the teachers would also explain more clearly, and teach things that you don't understand. I wish they would encourage and guide me and find my strengths. ……. The books have small sized letter. The higher the classes, the smaller the size of letters in the book. I wish the books had bigger letters! (Adolescent girl, 16 years, with a visual impairment at an inclusive school, K3)
>
> We don't have books [in Braille] and when teachers write on the white board, it is difficult for us…. because of this it is difficult to study (A girl who is visually impaired, Participatory workshop, Kavre)

In addition, those who were deaf and visually impaired repeatedly called for better resources which could help them to access lessons. These included films and other visual learning materials with subtitles, having more sign language terms to help explain topics (for the deaf), audio books which could be listened to on the phone, more books in Braille, more assistants to help with scribing. Their recommendations also included having more disability-friendly training for teachers, a more inclusive curriculum, and having better accreditation for special educational needs (SEN) teachers.

6.2.2 RECREATION TIME AND SPORTS IN SCHOOLS

Many adolescents described having friends in school, and even more commonly in the hostel. Friendship was important for 'having fun', and for support, and vital for their well-being.

Keeping fit and active were also seen as key to their health and well-being. However, there was a recurrent theme of experiencing exclusion from clubs, from school sports and games, and the playground was a difficult environment for some. This theme was not only limited to school settings, but also reiterated as an issue when home in the community. There seemed to be a variety of reasons for their exclusion- the teachers or other students' attitudes, young people's own attitudes such a fear of being hurt, or a challenging playground environment in inclusive school settings.

> They tell me that I don't see, so they tell me not to play. So, I don't play much….. So, I stay in my room and write if I want to.
>
> Interviewer: How do you feel at those moments, when your friends say such things?
>
> I feel very bad when they tell not to play. Everybody likes to play. It feels bad but let it be. (16-year old girl with a visual impairment)
>
> I should receive same rights as the able-bodied people. I can't play what I want to play because the teacher points out my disability. They say I can't play. I can't even participate in events that is to do with study [like a quiz] …. (Adolescent girl with a physical impairment)

6.3 Health

AWD said it was important to be physically healthy, but several experienced ongoing poor health, with repeated visits to hospitals, often resulting in time off school. Barriers to accessing health services included distances to the hospitals, costs of treatment, and the need to have an interpreter/translator for those with hearing impairments. For those living in hostels, the need to call a parent to come to collect them from a hostel, and then take them for treatment was an added complication. Economic factors further compounded those challenges. These issues are described here by a partially sighted 16-year-old girl living in a hostel who explained why she didn't want to call her mother when she was ill:

> I don't know…. Mum told me that she'd take me for treatment. Mum also doesn't have immediate cash. We shouldn't give her trouble. Those who don't understand, give trouble. Poor Mum, she's also not healthy. She also suffers from the same problems that we suffer from. The hospital is also far. (16 year old adolescent with visual impairment)

Access to rehabilitation services for those who needed these services, such as access to walking aids, was limited. Few young people appeared to benefit from these services, or their assistive device was ill-fitting.

The issue of sexual and reproductive health was explored, but not in any depth. The overall theme was of access to some limited information through schools, for example some information provided on menstrual health, but otherwise was not comprehensive. Again, the young people asked for more inclusive resources, such as more visual resources for those who are deaf.

6.3.1 PSYCHOSOCIAL HEALTH NEEDS

A prominent theme was of experiencing **poor psychosocial health**. There were some examples of great resilience shown by young people, despite very difficult circumstances, but the overall picture was of substantial **emotional health needs** of AWD not being recognised and/or addressed. This manifested in a variety of ways; three AWD expressed suicidal thoughts, young people in tears in the interviews as they described the difficulties in their lives, and the sadness at dropping out of school. There were also examples of low self-esteem, bullying and discrimination in the home, school, or community, often resulting in their exclusion and lack of participation in activities, feelings of being isolated and lonely, and concerns about their deteriorating health conditions and/or ongoing rehabilitation needs. Some of the feelings of despair came in discussions of where young people felt they were on the 'ladder of life' (1 being the worst life and 9 being the best life). Here, one young man described how sad he was to have dropped out of school, because of the lack of parental support:

> My life isn't that great, so I think it is because I don't get to study, and it is difficult for me to communicate as well. I am uneducated, and I feel like I can do nothing. I can't communicate with anyone in the community and in the house either, so I kept it at 2. I was studying really well until 2nd Grade but then I had to leave the education (Adolescent young man, 18 years, who had dropped out of school)

> Because of such talks, it affects our mental health…. I hope my neighbours didn't say such things about me (Young woman, 18 years, dropped out of school, with challenging health issues)

Photo: Girls only group, Sindhupalchowk

Another young man explained how he felt his parents blamed him for an accident at school where he lost his hand. He does not feel they are supporting him with his plans for the future, and he does not feel he can talk to anyone:

> I only get suicidal thoughts when parents keep on scolding me. I feel like committing suicide (Adolescent boy, 16 years, with physical disability)

A 19-year-old describes how supportive her family is, but she hides her anguish from them, and also from her friends. She feels guilty and ashamed at having to depend on others, due to her cerebral palsy, which makes it very hard for her to walk. She has had repeated treatments and has a walker, but she still struggles to be mobile. Her family moved to the town, so she has access to school, but life is still very hard:

> I don't think I have good life in anything. I cover my face in blanket and cry every night. My eyes are swollen in the morning and my mother asks what's wrong in the morning, I tell her it's the wind. I

> get really sad. I don't think this is life. It's better to not have a life than have this life. (Young woman, 18 years, with physical impairment)
>
> I used to feel that everybody else was going to school and only I had to miss the schools. I used to feel bad………… I was not jealous towards others, but I just felt bad about myself (Adolescent girl, 14 years, with physical impairment)

It was also common to find how despite these difficulties, a number of the young people felt they are unable to share their worries, sometimes not wanting to place a burden on others.

Two cases of adolescent young woman openly described experience of physical abuse experienced in the household; one young woman described how she was hit by her brother when she made mistakes with household chores, another described how she was forced out of the home. Adolescent girls more commonly described fear about going out alone unless they were accompanied, which further then confined them to their homes.

6.4 Transitioning to the workplace

Being able to work and have a good job were seen important for a good life- young people were aspirational and wanted to be able to work, seeing this as important for their independence, and so they could also contribute to the family. Among those who had finished or dropped out of school, none of them were in employment, and commonly, doing little at home, 'If I could get to do things which I can do [like sewing], maybe I can move ahead', or ' If I could get access to employment opportunities and if I could better treatment for my illness, I feel I would have a better life.'

Photo: Adolescent boys prioritising their key issues

However, a key concern for almost half of those interviewed and in two of the focus groups was the limited work opportunities they felt there were in their future. It was particularly highlighted by young people who were deaf, but was a key issue across all impairment groups. Their concerns included very limited opportunities being available to them for further education or vocational training, and/or poor-quality skills training. This made them concerned about whether they for the transition into the workplace. For example, in one special school, all the older students followed an engineering skills course, but the girls expressed their lack of interest in this and were left feeling unclear about the kind of job they could transition into, finding there were limited options. In another example, AWD continued to be offered courses like candle making and incense making, but like other young people, they wanted a variety of opportunities.

> For those with disability, they should be provided with trainings that they could do and are interested in (Participatory workshop, Sundalpauchuck)
>
> We need to develop skills based education and then livelihoods will be easier, for this training we need quality education (Participatory workshop, Biratnagar)
>
> If there were trainings and if I was encouraged, then I can move ahead.
>
> What kind of trainings would you want?
>
> Computer trainings. (Young woman, 19 years, with a physical impairment)

The quality of the training courses available was also questioned in about one third of the interviews and in two focus group discussions. For example, all students in one school highlighted the poor quality of their engineering skills course due to lack of inclusive teaching and materials, as well as wanting a wider choice of skills training. The attitudes of employers and lack of equal opportunities was also highlighted in a small number of interviews:

> People think that disabled people can't perform any task. They think blind people can't walk like other, so they can't work………My other normal friends will get more opportunities than me. (Adolescent girl with low vision, 17 years, at inclusive school)

Another theme was the low levels of knowledge about career opportunities, and of the steps they would need to take in pursuing such opportunities. For example, in one focus group discussion, almost all the girls who were deaf wanted to be a waiter in a restaurant, as they said this would not require them to communicate extensively. Interestingly, one young woman described her aspiration to work in the beauty industry after recently seeing a deaf model on television. Some of the AWD described want to conduct work '*like the youth researchers'*, which suggested the importance of peer role models in supporting AWD to plan for the future.

Parents interviewed expressed real concerns about their child's future and often expressed a lack of hope and/or aspiration for their child's future.

> If we could teach her some skills which can help her to lead an independent life that would be really wonderful. That would help her life better. That school doesn't have classes beyond 12, so they will not be able to get education beyond grade 12. (Parent of adolescent boy with multiple impairments, 14 years)

6.5 Life in the community

Family life is the centre of life in the community for AWD. Many of the AWDs, because of boarding in hostels, only returned home for short periods of time, perhaps 2-3 times a year, and so their social networks within their communities were often restricted.

Friendship was really important, and if accompanied by friends or family members then AWD might participate in the social activities such as visiting the temple or attending weddings. In approximately half of the interviews they talked about some level of participation in the community. However, in more than half of the interviews, they also described difficulties experienced with participation in community life, and were often described as sources of sadness.

Barriers to participation included stigma and discrimination in various forms, physical difficulties in accessing community settings unless accompanied, needing to be accompanied, and choosing to self-exclude. One Youth Research Associate interpreted some of the experience as a 'passive discrimination', in that people did not overtly discriminate, but also made no effort to actively include them.

> I attend some of the functions which are of close relatives. But, even when I attend those functions, I am the only one to sit on the chair. We have practice of sitting on the floor to eat and they arrange a chair for me. I really feel bad about it. (19 year-old young man with a physical disability)

Approximately one third of AWD described rarely leaving the house. This seemed to be particularly the case with young people who were deaf, and there was some evidence that it was more pronounced in rural contexts where the isolation was more acute. For example, a deaf young person expressed not being able to meet up easily to use sign language with another deaf young person. In most cases mobile phone use was limited or non-existent for staying in contact with friends:

> In the community as well, there is problem. It is difficult to communicate so they do not show much interest in communicating with us. We can't talk so we don't interact with them much…………………… It is difficult because of communication gap (Adolescent boy who is deaf)

> I can't go anywhere. I watch T.V. and sit, go to my neighbours, my days are spent like this [What do you prefer doing during the day?] I don't have much work. Sometimes I sleep, sometimes it's just like that. (Young woman with a physical disability, 18 years, dropped out of school)

In some cases, the lack of assistive devices exacerbated the poor physical access, as described here by a young woman of 19 years who has always had to rely on her brother to carry her to any cultural events. She says this was fine when she was a smaller child, but now she is bigger it's too hard to carry her, and she also hates the community attitudes:

> Even if I'm interested [to attend an event], when people ask me, I tell them I'm not interested. I don't want them to pity me, I hate when they use the word '*bichara*' (pity). Instead of people saying you can do this and that and can get there, I don't like people who say '*bichara*' (Young woman, 18 years with a physical impairment)

6.6 Disability Rights – the Disability Card

Two thirds of those interviewed shared their experiences about accessing a Disability Card, and the majority were in receipt of a card. However, the key recurring theme in almost every case was of delays experienced, in some cases resulting in waiting years to get the card. The main reason was administrative hurdles required, combined with low levels of knowledge in the family about the benefits of the card and how to get one. In three cases they thought they had the wrong coloured card which resulted in no financial benefits, and in another three cases they were not in receipt of a card, despite their impairment. For example, one adolescent who was deaf described how he dropped out of school because he had no disability card, and his parents were therefore unwilling to support him to continue in his studies.

6.7 Cross-cutting issues

6.7.1 POOR PHYSICAL ACCESSIBILITY

Challenges related to physical accessibility were a key theme in the home, school, hostel, health services and community environment. It was particularly highlighted by those with physical and visual impairments. The situation was further exacerbated by post-earthquake conditions in two sites (Kavre and Sindalpauchuk) where most families were still living in makeshift conditions. In some cases, the environments were felt to be unsafe, with examples of serious accidents.

In rural areas, secondary schools or colleges were at some distance from homes, and those living at home highlighted how difficult it was to get to and from school. It was also a main reason for dropping out, explained here by a young woman of 18 years who reported having real difficulties with walking which caused her pain and she had no assistive device,' My school was also far away. It used to take exactly an hour for me to reach school. So, since it was far, I decided to quit'.

Another girl described how supportive her family was as they moved to the town so that she could attend college more easily- she used to squat on the ground and drag herself to school, and the distance proved too much when she transitioned to college. However, even in the town, she had to rely on her family to take her on a bike to school, and frequently missed school days when family members could not take her.

> My parents used to carry me there when I was young but when I was in grade 8, I was embarrassed, so I used to drag myself there. ………… I used to drag my feet and do this with my hand. Like how you would sit in the toilet (Young woman with a physical disability, 19 years)

Even within the school and hostel environment, there were many examples of poor access such as stairs for which the young person had to be carried up, or playgrounds that were hard to negotiate for a person with a visual impairment. Sadly, there was also two cases of serious accidents, because of unsafe conditions.

6.7.2 INACCESSIBLE WASH

Most notably, the lack of accessible WASH facilities made lives very difficult. One third of young people discussed the challenges in their homes of having no toilet or inaccessible toilet facilities which they struggle to use, and of the difficulties they faced in trying to collect water themselves for bathing. A young woman of 18 years described how difficult it was to walk the distance to her neighbor's toilet, because they are still living in a makeshift house since the earthquake, and did not have the resources to build a toilet:

> If I go to the toilet then its fine. Or else I urinate on my clothes. It happens sometimes during the day. (Young woman with physical impairment, 18 years)

For those living in hostels then difficulties with the toilets was again an issue; the toilets were dirty in some cases, and young people were fearful to access the toilets at night as they were situated outside of the building; this was particularly highlighted as a safety issue for adolescent girls.

7 The role of youth researchers with disabilities- lessons learnt

> If people with a disability, like me, get exposure and opportunity, they can to do anything. Because, if a disabled person can do research where we had to go to field, write reports, and do different other things, we are able to do anything…disability is not a barrier. (YRA with visual impairment)

The YRAs worked as a team; working in pairs to visit most households. The research process was a journey; with knowledge increased and skills developed over the 3-week period. All YRAS were very positive about the experience and reflected on how they learnt from the lead co-researcher, as well as from their peers.

Research skills acquired included active listening, rapport building, observation & field notes, understanding the role language can play, and specific skills in conducting one to one interviews & focus group discussions. **Other skills** acquired included communication, coordination, time management, analytical and team building skills.

There was an assumption that, as a young person with a disability, they would bring knowledge and understanding of living with a disability. However, it emerged that this assumption was not much different from perceiving people with disabilities as a homogenous group. It was highlighted how YRA's knowledge about impairments did not extend much beyond their own. One YRA reflected on Day One that he was surprised that people understand disability as '*One basket for all*', whereas in fact there were diverse experiences, dependent on the impairment.

Building their own **confidence** was a key motivation reflected upon by YRAs, and they also saw they had important **responsibilities as role models** towards both the adolescents that they interviewed and their parents:

> It was very difficult for me in the beginning, then …………… I realised that if we are not strong, how will the young people become strong in future? I felt that we are here to encourage them and should be strong. I also discussed this with [my co-researcher]. Then I was able to conduct the interviews with confidence (YRA with physical impairment)

> As I deaf person, I haven't heard if another deaf person working on research. So, I feel that I am the first youth deaf person to become a deaf researcher. So, my confidence level has been upgraded too. If I get similar opportunities, I can utilise the skills I learnt to the fullest. (YRA who is deaf)

The **emotional demands** of the research were a key issue for every researcher. The interviews had their impact on the youth researchers, sometimes provoking thoughts on their own experience of growing up with a disability. The YRAs felt they became more emotionally resilient over time, but this does need to be managed, with support available for the YRAS.

Overall, it was a **journey of empowerment for the YRAs**, as reflected upon here:

> Involving us in the research has empowered us too. You provided us with training, because we didn't know much about research. We were able to bring something more on the research too. (YRA with visual impairment)

The co-facilitation of the research afforded various **additional benefits**. The YRAs played an important role as **key informants**, providing valuable contextual information from the perspective of a young person, a person with a disability, and/or within the Nepali context. However, working in more remote rural areas was new for some, so it cannot always be assumed that there is a 'shared language'.

The YRAs played a **strong role in the analysis** in final participatory analysis workshop, and this brought a valuable range of different perspectives into the analysis and the triangulation of the data. The YRAs presented preliminary findings to the Plan International Nepal senior staff, highlighting their **role as advocates**, informed by their engagement in the research process.

The **challenges** included a very demanding multi-faceted role for the lead researcher, who provided on-going mentoring and support for the YRAs, as well as co-facilitating the interviews and logistical support. The fieldwork was physically demanding, and accessibility and an inclusiveness of the interview settings was sometimes difficult in the remote rural areas.

8 Discussion and recommendations

Our research demonstrated the importance of using young people with disabilities as Youth Research Associates (YRAs) and how this enriched the research process. The result was a team of YRAs who co-facilitated the research, taking on different roles alongside experienced researchers. Other benefits included the experience the YRAs brought to the research design, the rapport built with the adolescents, and the importance of them as role models in the process.

For adolescents with disabilities, several priorities were important for their well-being. This included key was support from family and friends, and access to a quality education, with real opportunities for work in the future. They described a wide range of challenges which they face, and their priorities for improving their lives.

It was clear that times of transition can be particularly difficult; transitioning to secondary school or college and transitioning into employment. The poor quality of their educational experiences was a very real concern for them, and opportunities for skills or vocational training were commonly narrow. They were aspirational for the future, and yet some of them saw only some jobs as available for them.

One key priority from this research was the psychosocial health needs of adolescents with disabilities, and finding way to reduce their isolation, in the home and the community. Many of the young people were in hostel settings and there was a gap between the home/community and school environment that appeared to result in limited social networks when they returned home for short periods, with potential implications for their inclusion in the longer term.

Communication gaps are particularly acute for those who are deaf or have a hearing impairment, and they are often incredibly isolated, even in their homes. Although the YRAs used mobile phones and social media to stay linked with friends and family, this was not observed in the adolescents interviewed. In fact, schools and hostels did not encourage use of phones. A better use of social media and technology may be a way to improve the lives of young people with different learning and communication needs.

Adolescents inevitably want more independence, and it was perhaps not surprising that as they get older they do not want to be carried to school, or to be helped with toileting and bathing, so these access issues become an increasing priority. Keeping fit and healthy and having fun with recreational opportunities were deemed important for better life, and currently such activities were generally not inclusive or available.

Photo: Adolescent girls in the participatory workshop

The disability card and the benefits were important for families, especially when poverty exacerbated the challenges experienced, but in practice many had experienced long delays in accessing the card, and administration barriers and information gaps were highlighted.

Despite these many challenges, the voices of the adolescents with disabilities was strong, demonstrating the transformative role that they can play in improving their own lives. One group of AWD described that this was the first time anyone had asked them these questions, and so there is a real opportunity to now build on this research.

9 Recommendations

These recommendations are drawn from the suggestions of the AWDs, YRAS, Plan International Nepal and CBM Nepal staff, in discussion about the research findings. These recommendations can serve as a starting point for discussions. The participation of young people as researchers also emphasise the importance of fostering the participation of adolescents as change agents in these recommendations, where possible and feasible. Given the decentralization of services within Nepal, the opportunity for addressing these recommendations is *at local government level* as well as *nationally*.

- Urgently address psychosocial health issues as a priority; working with young people to see how it can best be addressed. Explore peer support networks, and engagement of young people in the community to explore ways of addressing isolation. This might include ‘buddying’ or ‘mentoring’ programmes as a way forward. The specific vulnerabilities of adolescents who have dropped out of school or in transition to work is a priority.

- Work with parents and offer disability awareness training. This should include a specific package on communication skills, for parents of young people who are deaf.

  > *There should be institutions who give sign language training or communication training to the parents. The government should have a policy about how to increase awareness of parents about their children (Participatory workshop, boys and girls group, Deaf school, Biratnagar)*

- Improve the quality of the educational experience for AWDs; improving the training and support for teachers and improved educational resources. Explore better use of technology to improve access to quality education for AWD e.g. voice activation technology or access to more visual materials for young deaf people. Mobile phone technology could be better harnessed.

- Work with schools to improve inclusivity both inside and outside of the classroom. Inclusive sports are a key priority identified by young people:

  > I wish there were different sports for visually impaired so that we could play in a group.

- Build stronger linkages between the home and school, especially for young people away in boarding schools and hostels. This might take the form, for example, of a training package for families, co-facilitated by the young people themselves.
- Improve physical accessibility in home, school, and community environments, with a focus on accessible WASH.
- Ensure young people and their families are better linked to local organisations which can facilitate access to health and rehabilitation services.
- In post-earthquake settings, priority should be given to the specific needs of children and young people (and adults), living with a disability. Temporary shelters need to be accessible, where feasible, and accessible WASH facilities should be a priority.
- Explore the use of peer role models to meet the needs of adolescents with disabilities and their families. This could be multi- faceted and include the use of positive peer role models to encourage access a wider range of training/vocational training and livelihoods options, support networks to address the issue of isolation, and engagement with family members.
- Address specific needs of older adolescents in transitioning to the work place. Improve awareness amongst adolescents and their families about training opportunities and livelihood options. Conduct awareness raising with employers, support mainstream vocational training to be inclusive, and engage with peer role models to raise awareness about opportunities and change attitudes.
- Improve access to SRH information for AWD in a format that is inclusive and accessible in both school and out-of-school settings.

- Increases awareness of the Disability Allowance and other entitlements to families with children and adolescents with disabilities. Advocate for streamlining of the application process for the disability card; explore options for decentralising the processes.
- Increase engagement between DPOs and adolescents with disabilities and their families to support their participation in planning, implementation and monitoring of locally relevant programmes which address their needs.
- Strengthen disability programmes at a national and local level so that there is increased awareness of the specific needs of adolescents with disabilities. This should include strengthened inclusion of adolescents with disabilities within mainstream programmes

Photo: Adolescent boys discussing their issue with Youth Research Associate

10 References

1. Sawyer, S.M., et al., *The age of adolescence.* The Lancet Child & Adolescent Health, 2018.
2. Bernays, S., et al., *Being an 'adolescent': The consequences of gendered risks for young people in rural Uganda.* Childhood, 2017: p. 0907568217732119.
3. Patton, G.C., et al., *Our future: a Lancet commission on adolescent health and wellbeing.* The Lancet, 2016. **387**(10036): p. 2423-2478.
4. World Health Organization, *Global Strategy for Women's, Children's and Adolescents' Health, 2016-2030 at http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/*. 2016.
5. United Nations, *Sustainable Developmnt Goals at https://sustainabledevelopment.un.org/*. 2015.
6. Organization, W.H. *Global accelerated action for the health of adolescents (AA-HA!): guidance to support country implementation: summary at http://www.who.int/maternal_child_adolescent/topics/adolescence/framework-accelerated-action/en/*. Global accelerated action for the health of adolescents (AA-HA!): guidance to support country implementation: summary 2017 [cited 2018 16th jan].
7. Dornan, P. and K. Pells, *From Infancy to Adolescence: Growing Up in Poverty.* Young Lives Policy Paper, Oxford: Young Lives, 2014.
8. Dornan, P. and M. Woodhead, *How Inequalities Develop through Childhood: Life course evidence from the Young Lives cohort study*. 2015.
9. Stewart, D., *Transition to adult services for young people with disabilities: current evidence to guide future research.* Developmental Medicine & Child Neurology, 2009. **51**(s4): p. 169-173.
10. Winn, S. and I. Hay, *Transition from school for youths with a disability: issues and challenges.* Disability & Society, 2009. **24**(1): p. 103-115.
11. Banks, L. and M. Zuurmond, *Barriers and enablers to inclusion in education for children with disabilities in Malawi at http://disabilitycentre.lshtm.ac.uk/files/2014/07/Report-on-inclusion-in-education-for-children-with-disabilities-in-Malawi_FINAL_large-print_1.pdf*. 2015.
12. Kuper, H., et al., *The Impact of Disability on the Lives of Children; Cross-Sectional Data Including 8,900 Children with Disabilities and 898,834 Children without Disabilities across 30 Countries.* PloS one, 2014. **9**(9): p. e107300.
13. Kuper H, M.-v.D.A., Wing K, Danquah L, Evans J, Zuurmond M, Gallinetti J. , *The Impact of Disability on the Lives of Children; Cross-Sectional Data Including 8,900 Children with*

Disabilities and 898,834 Children without Disabilities across 30 Countries. PLoS One, 2014 **Sep 9;9(9):e107300**.

14. Hartley, S., et al., *Community Action Research in Disability (CARD): An Inclusive Research Programme in Uganda.* Disability, CBR & Inclusive Development, 2017. **28**(1): p. 5-92.
15. Singal, N., *Doing disability research in a Southern context: challenges and possibilities.* Disability & Society, 2010. **25**(4): p. 415-426.
16. Wickenden, M. and G. Kembhavi-Tam, *Ask us too! Doing participatory research with disabled children in the global south.* Childhood, 2014. **21**(3): p. 400-417.
17. United Nations. *UN Charter on the Rights of Persons with Disabilities*. 2006 [cited 2013 4th Sept]; Available from: http://www.un.org/disabilities/default.asp?id=150.
18. United Nations. *The UN Convention on the Rights of the Child*. 1989 [cited 2013 4th Sept]; Available from: http://www.unicef.org.uk/UNICEFs-Work/Our-mission/UN-Convention/.
19. Percy-Smith, B. and N. Thomas, *A handbook of children and young people's participation: Perspectives from theory and practice*. 2009: Routledge.
20. Shaw, C., L.-M. Brady, and C. Davey, *Guidelines for Research with Children and Young People available at http://www.nfer.ac.uk/nfer/schools/developing-young-researchers/ncbguidelines.pdf*. 2011, National Children's Bureau London.

21. Morris, J., *Don't leave us out: involving disabled children and young people with communication impairments*. 1998: YPS.

22. Government of Nepal, *Nepal Living Standards Survey at http://siteresources.worldbank.org/INTLSMS/Resources/3358986-1181743055198/3877319-1329489437402/Statistical_Report_Vol1.pdf*. 2011.

23. WHO and World Bank, *World Report on Disability* 2011, WHO: Geneva available at http://www.who.int/disabilities/world_report/2011/en/index.html.

24. Development Resource Centre, *Final Report on:Improving the Sexual and Reproductive Health Status of Young Women in Nepal (Finnish Project II)*. 2008: Kathmandu: Development Resource Centre

25. Development Resource Centre, *Baseline Study Young people's sexual and reproductive health status in 5 districts of Nepal*. 2009: Kathmandu: Ministry of Health and Population (MoHP) - Nepal & Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ).

26. CARE, *The cultural context of child marriage in Nepal and Bangladesh: findings from CARE's Tipping Point project at http://www.girlsnotbrides.org/reports-and-publications/care-tipping-point-project-nepal-bangladesh/*. 2016.

27. UNFPA, *Engaging men and boys, communities and Parents to End Violence against Women, Child Marriage and Other Harmful Practices in Nepal http://nepal.unfpa.org/sites/asiapacific/files/pub-pdf/ICRW.pdf*. 2014.

28. Eide, A.H., *Living conditions among people with disability in Nepal.* SINTEF Rapport, 2016.

29. Young Lives, *young lives and well-being in the context of poverty.* 2008.

30. Messiou K, *Encouraging children in more inclusive ways.* Brit J Spec Ed, 2008. **35**(1): p. 26-32.

31. Alderson, P., *Children as Researchers: Participation Rights and Research Methods*, in *Research with Children: Perspectives and Practices* P. Christensen and A. James, Editors. 2008, Routledge: London. p. 276-290.