

# Strengthening the Voices of Adolescents with Disabilities in Nepal: A research project

## Youth-Friendly Executive Summary & Recommendations

### 1 WHY DID WE CONDUCT THIS RESEARCH?

We wanted to understand what were the most important issues which make a difference to the lives of adolescents with disabilities (AWD) in Nepal. We wanted to talk to AWD about their **wellbeing**, what they needed for a **'good life'**, and where the gaps were, so that this can feed into policies and programmes.

Adolescence is an important life phase between childhood and adulthood, where, if given the rights opportunities, adolescents and young adults can *'transform our futures'*<sup>1</sup>. We talked to a total of 52 adolescents of 14-19 years old, and to some parents and teachers (12 in total). We talked to 27 girls and 25 boys across four districts in Nepal who had different types of disabilities; physical, visual, and hearing, and a small number with multiple impairments.

We trained a team of seven Youth Research Associates (YRAS) who had different types of disabilities, and they helped to conduct the research. We wanted the voices of adolescents with disabilities to be at the heart of the research, embracing the idea of 'Nothing about us, without us'. 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 in different ways.

We talked to them on their own ('one to one' interviews) in their homes or in school, and we talked to groups of young people in three participatory workshops. We asked them what was important for them or a good life, and what was important to improve their lives. This is a youth-friendly version of the report and a detailed report is also available.



Photo: Analysis workshop with Youth Research Associates, sharing their interpretation of priorities

<sup>1</sup> Patton, G.C., et al., *Our future: Lancet commission on adolescent health and wellbeing*. The Lancet, 2016. **387**(10036): p. 2423-2478

## 2 WHAT DID THEY TELL US?



Here is a summary of the key issues we were told:<sup>2</sup>

- Our families are really important to us, and it is important to feel loved and cared for. But sometimes life at home can be difficult. For some of us, there is a **communication gap** with members of our family, and we feel they don't always understand our needs. This can be particularly difficult for young people who are deaf.
- **Education** is incredibly important to us, but the quality is not always good. Some individual teachers are helpful, but there are also many examples of poor quality teaching which does not meet our learning needs. There are few educational materials, such as in large font or audio books, or good visual materials (for the deaf), and we really need more. We get limited accessible information about sexual and reproductive health.
- Many of us have experience difficulties when we go to secondary school- a time of **'transitioning'**. These schools are often at greater distance from our homes, which makes access harder. Many of us don't have assistive devices, such as a wheelchair, to help us.
- Many of us need help with our **'emotional health'**. We can feel depressed with our situation, and in some cases feel suicidal. This can be for lots of reasons; we are worried about health and treatment of our condition, we can be worried about the future, and we experience stigma and discrimination. We often have no-one to talk to, and we don't always find it easy to share our worries as we also don't want to be a burden. *"I used to feel that everybody else was going to school and only I had to miss school. I used to feel bad..... I was not jealous towards others, but I just felt bad about myself"* (Adolescent girl, 14 years, with physical disability)
- **Our friends** are extremely important to us, and they can help to us participate in activities, but a large proportion of us will rarely leave our homes. Very few of us are members of local organisations and clubs, and we can feel very isolated. It can be even worse for those who have dropped out of school or are not working. We want other people to make more effort to include us.
- **The physical environment** of our schools and hostels can be **inaccessible**, especially for those of us with a visual or physical impairment. In some cases, this has led to accidents. Some of us are living in homes still affected by the earthquake and that makes our lives very difficult. We still struggle to use the toilet and bathing facilities, and this is a particular challenge for adolescent girls where privacy and safety in using WASH facilities is really important.
- **Being able to work and have a good job** is very important for our wellbeing, but the step to the workplace can be very hard, and it is often unclear how we get work. There are only limited higher education or skills

<sup>2</sup> These key points are a summary and presented in a youth-friendly format and cannot be taken as direct quotes. See the full report for direct quotes.

training courses available, and these are often of poor quality. We don't really know what work opportunities there are for us.

- Many of us have additional health and rehabilitation needs which are not being met, and the payment for treatment or transport to the service is a major barrier, especially if needed on a regular basis. Few have access to suitable equipment ('assistive devices').
- For a healthy life, we want to keep physically active, but often we are not included in **sports activities** in schools and communities, and even in special schools there are few opportunities, and we feel left out.
- Most of us have a **Disability Card**, but it hasn't been easy for our families to get these cards, and we have experienced lots of difficulties with administration, sometimes with delays of years to get the card. Even now, not all of us have the correct card, and so receive few benefits.
- The **Youth Research Associates** felt empowered by their participation in the research; with increased knowledge and confidence in their new skills. They often felt very emotional in listening to the stories which were shared with them, and it was important to have support for this.

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

### 3 RECOMMENDATIONS (WHAT NEEDS TO BE DONE)

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These ideas have been put together by talking to the young people, researchers, and staff at Plan International Nepal and CBM Nepal staff. This is a starting point only!

Discuss these ideas in your own groups, and with your family and friends, and come up with more ideas about what is important in your own environment. Remember you are also part of the solution – use this research to **strengthen your own voice!**

- ◎ Urgently address 'psychosocial health' (emotional health) issues. Find ways to address the isolation and improve support networks. It might be that a peer support programme could help, and especially for AWD who have dropped out of school, or who are not working.
- ◎ Find ways to work with parents and other family members and offer them disability awareness training. This should include a 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" (FGD, boys and girls group, Deaf school, Biratnagar)*





- ⊙ Improve physical accessibility in home, school, and community environments, with a focus on accessible WASH (Water, Sanitation and Hygiene).
- ⊙ In post-earthquake settings, priority should be given to the specific needs of those living with a disability. Temporary shelters need to be accessible, and accessible WASH facilities should be a priority.
- ⊙ Improve the quality of education, with improved educational resources, so we find learning easier. For example, better use of voice activation technology, for those with visual impairments, or visual materials with those who are deaf. Mobile phones could also be used to facilitate a peer support network. Out of the classroom, improve access to sport. “I wish there were different sports for visually

impaired so that we could play in a group”

- ⊙ Explore how young people with disabilities can be role models to adolescents with disabilities and their families. They can be really important role models! For example, they can provide information on their experience in the workplace, and what was useful for them in transitioning from school to work.
- ⊙ Look at the specific needs of older adolescents who want to work, as this can be a difficult time. Conduct awareness raising with employers, and ask for mainstream vocational training to be inclusive.
- ⊙ Improve access to Sexual and reproductive health information for AWD in a format which is inclusive and accessible, in both school and out-of-school settings.
- ⊙ Increase awareness of the Disability Allowance and other rights 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 so that it is not so complex.
- ⊙ Increase links between the families with local organisations such as Disabled People’s Organisations. Ensure the young person’s voice is central to any planning for improving their lives, in line with the UN Charter on the Rights of the Child and the UN charter on the Rights of Persons with Disabilities. This includes involving them in research about their lives.



- ⊙ Strengthen disability programmes at a national and local level so that there is increased awareness of the specific needs of AWDs. This should include strengthened inclusion of adolescents with disabilities within mainstream programmes.

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