Nepal: Let's work together Community based action for inclusion

"We can study with and play with our friends."

"We see our children improve in skills, and in habits, and getting opportunities to study and have fun."

"We need special skills to teach this type of child, but being in the ordinary school gives them opportunity to study, as well as for the non disabled children to learn something about disability."

# 1. The wider context - Nepal

In the Himalayan Kingdom of Nepal, services and support for disabled people and their families are scarce. The mountainous terrain and lack of transport and infrastructure add to the practical difficulties.

The population is about 23 million, and most people (90%) live in villages with agriculture as the main livelihood. Nepal remains one of the poorest countries in the world and the disparity between its rich and poor inhabitants is increasing. Because of the poor economy there is increasing migration of workers abroad, mainly to India, and this is having a significant impact on family life. Hinduism is the religion of the majority (90%) and there are small Buddhist and Moslem minorities. Since 1990 Nepal has been a constitutional democracy. However, there have been frequent changes of government and there is increasing unrest by militant groups.

Nepal is a very hierarchical society with a similar caste system to India. Many groups are marginalised. Women and girls suffer a universally low status making gender discrimination the most serious form of discrimination in Nepal. Children from lower castes, refugees and working children as well as disabled children are further marginalised.

Social attitudes towards disabled people and their families are often very negative. They may include beliefs that disability is contagious and so interaction with disabled children and adults and even their families is often discouraged. Sisters of disabled people may have poorer marriage prospects and disabled people are not allowed to inherit property. The mother of the child is often blamed for the disability.

Education is mainly provided by His Majesty's Government (HMG). There is also a growing private/commercial education sector, mainly in urban/bazaar areas. Education services are still very limited and presents a considerable challenge:

* Only six of Nepal's 75 districts are designated compulsory education districts so far, though the system of compulsory education is being extended.
* There is a very high drop-out rate with only 37% of primary school children completing education up to 13 years. This is due to a variety of factors including the demand for children to do manual work, especially in the villages. Social attitudes include the view that it is not necessary to educate girls, members of lower castes, disabled children and others.
* In rural areas the literacy rate is still only 33% and only 10% for girls.
* The education system remains very under-resourced. Access to educational materials is a real problem for the majority of primary school children. The system is very hierarchical and examination-focused. A child who fails end of year exams is held down and may remain in the same class with much younger students for several years. So, even though primary education is free and theoretically universal, the reality for the majority of children is that school may be neither accessible nor relevant.

Since 1998, the Special Education Sector of the Ministry of Education has developed a more inclusive policy. Special schools and hostels are being closed and disabled children will attend ordinary schools.

# 2. The Community Context

In two Districts of Nepal, Kaski and Syangja, parents and their disabled children are working together with a community-based organisation (Community Based Rehabilitation Service, or CBRS) to promote inclusive education opportunities and support.

CBRS has been working for and with disabled children and their families since 1995. CBRS clients have physical and or learning disabilities, and CBRS networks with and refers to and from other local organisations working with other types of disability.

CBRS works closely with the families of disabled children in all activities, such as community awareness, home visits, and parents groups for self-help and advocacy. During the last two years, parent groups, CBRS project staff and local school and education officials have worked together to enable more physically disabled children to attend ordinary schools in their local areas. Support to students, teachers and families is offered through a variety of activities, including awareness programmes in the schools attended by disabled students and teacher training programmes.

How have families been involved in this?

# 3. Families' views about education

In CBRS, development of ideas about education was first stimulated in 1997 through some discussions with parent groups and a special education advisor from the Ministry of Education. Parents shared different ideas and considered some different models or systems of education.

Parents identified some of the most common feelings and wishes:

* We want our children to receive an education;
* Most of us think that the development of opportunities to go to school is not just the responsibility of the government but should be a joint effort between the government and the local community;
* Our time is limited but we would like to play a part in the life of the school;
* Our knowledge about our own children is important and should be conveyed to teachers so that the child's education and quality of life can improve;
* We would like to see that teachers are willing to work with us;
* Local recruitment of teachers would help promote stability and cooperation;
* A member of the District Education Committee, ideally a parent of a disabled child, should be appointed to represent the children with special needs;
* We prefer school models and systems where our children remain with us in the family setting;
* We would like to see the children learning things to help them contribute to the family and the community, especially for those in rural families;
* We would like to see more skills training in the curriculum and not just academic content.

A report of these discussions, "Parent Voices", was published and has been used by the CBRS project and the Special Education Department in further planning.

# 4. Family involvement in project management and education policies

CBRS has an advisory group to give parents and disabled people themselves a direct "voice" in the running and management of CBRS. The members, both men and women, represent different castes, different disabilities and different parent groups. This forum meets every 2 months to consider disability-related topics and project activities and to plan and make joint decisions.

The invitation to participate in the EENET project Family Action for Inclusion stimulated a lively discussion among members of the Advisory group. The new compulsory school system in some districts will enable more children to attend ordinary schools in future but parents expressed their fears of on-going difficulties:

"In town the child may be able to get to school in a wheel chair but in the village there are no flat roads"

"It is not easy; we see problems mostly with people's attitudes, including the teachers"

"You do see bad attitudes and very traditional views."

"When my son falls down, as his muscles are quite weak, often people will not help him up as they are afraid they will catch something bad from him. He doesn't like this and says, 'I am shy, mum'. This also means that he doesn't really like to go to school."

"It is very hard for the child if they get teased and we know that the teacher will sometimes take part or even start the teasing!"

"Only one of the teachers in school likes me: it would be better if they all liked me"

"Bishnu is seven and is now walking with a wheeled frame. He wants to go to school and his family is keen for him to go - none of them had an education and they live in a slum area. But the head teacher has so far refused to take him."

But parents also feel that attitudes are slowly improving:

"Now that there are some projects like CBRS, slowly people are learning more and becoming more understanding."

They appreciated the efforts and flexibility that enable some children who cannot get to school to learn at home:

"It is quite amazing what can be done with lots of practice and effort. In our District, there is a girl who has no hands and she does everything with her feet - eating, brushing her hair, everything. She has just passed her school leaving exams. A lot of time and energy had to be put in to achieve this. We should try to do the same for our children and work with CBRS field staff to get the best benefits."

"Children can also learn about colours, numbers and even letters. They can learn practical skills and crafts like sewing, knitting and painting in the home"

"You can involve them in income generating work as well."

In the meeting, we also discussed the practical financial problems of many families and as a result the project then started a new scheme to help the poorer families to find money for school fees, school uniform and stationery, either from local government or from other sources. In Nepal a child may be sent home from school if they do not have a uniform and some families cannot afford the clothes.

# 5. Family Involvement in Teacher Training

In October 1999, during a training course for government teachers of physically disabled children, the children themselves and one family member for each student -parents, sister, uncle or grandparent took part in one week and added their voice to the discussion:

"What we like about our disabled children going to school is:

* there is an opportunity for them to go to an ordinary school;
* the child can learn to read and write, play and have fun;
* the children themselves ask to go to school;
* their habits (e.g. washing,dressing) improve;
* the children like to be with ordinary children;
* their ability to play improves;
* their walking improves;
* it's good if the child can study to the highest level that school offers;
* the siblings of the disabled child also started to attend school

The children were also asked about their school experiences:

* We can study and play;
* I can sit with my friends;
* I like to see my friends fight and play;
* I like writing and to play ball;
* Sometimes other students hit me;
* Sometimes people tease us or say we can't walk properly but we still have lots of friends;
* The path to the school is hard and the path to the toilet is difficult.

CBRS set up the training and were aware that to include all these groups together was a new idea and could prove difficult within the very hierarchical structure in the education system and in Nepal society as a whole. For some families and teachers, this was the first time they have met properly, despite living in the same communities and being involved with the same children!

The 'risk' was worth it: to see teachers listen to what the families and children had to say and to let families in their turn hear the teachers perspectives; and to see the groups share their experiences and discuss issues openly for the first time was very new and exciting for everyone.

This teacher-training programme by CBRS is continuing and has had good results in motivating and supporting teachers who, until then, had no additional support or training to teach disabled students. An important focus of the training was to develop the role of the teacher as a resource person for the whole community and to work much more closely with the child's family.

# 6. Informal Education

One of the Advisory Group parents was involved in a system of non-formal education provision. This was offered not by CBRS but by another NGO in Pokhara to children from the poor slum areas and to poor families who would not otherwise send their children to school for any education. This system contrasts sharply with the more traditional education system, which is more formal, depends on rote learning and on very authoritarian control, including physical punishment. The classes in government schools are very large, 50-100 pupils. Some of the different characteristics of the non-formal system are:

* As many children have to do manual work to help support the family, class times are arranged around this;
* Education is based on interactive learning and play activities, including songs, drama, games;
* More emphasis is given to values of cooperation and supporting each other, and of mutual love and respect, both for each other and for their teacher.

# 7. Our plans for the Future

Some of our (CBRS, and included families) plans are to:

* Continue to try to help children get placements in ordinary schools and raise awareness of disability among other students;
* Try to get more educational opportunities outside the formal school context;
* Giving financial help to poor children, especially in the villages;
* Enabling children and young people to study locally. Some parents want to send the child away and this can create problems in the future;
* Helping to obtain equipment;
* Promoting good role models of disabled people who have studied and achieved like Mr. RD who is a university teacher in Kathmandu and has artificial legs. This can motivate others, including families who may think that their disabled member cannot do anything;
* Find sponsors for individual children and asking schools to give scholarships \* Lobbying government to give personal allowances for disabled students and to offer incentives to schools to accept them;
* Lobbying government to improve education services for ALL children;
* Continue the programme of training teachers with the participation of families and disabled children themselves;
* Develop a curriculum and learning materials to enable other projects to run a training programme.

# 8. Our advice for others

* It is important to raise the awareness of teachers and help them learn how to teach the child so that s/he does not feel different but feels loved. We need more contact with other parents and with teachers and also to raise the awareness of neighbours and the local community and other students.
* It is important to motivate the family and the community to regard education as of value.
* Work to change attitudes. Attitudes remain a major barrier. They still depend a lot on caste and on the traditional jobs that people do. It is important to work on our own attitudes and on others' attitudes towards all marginalised people.
* Place children in regular schools. This is a positive way to improve the attitudes of teachers and other students.
* Arrange meetings between professionals who work with disabled and disadvantaged people, people with disabilities and family members. These are helpful in enabling everyone to learn from each other and to understand each other's perspectives and problems. Meetings lead to positive joint decisions and action.

# 9. Sources of information

Sources of information have been the CBRS Coordinator and Management Team, as well as project records and papers. The Advisory Group discussion was videoed and a translated tape was sent of the discussion. The consultant was also able to meet with the Project Coordinator to discuss the story. An additional source was a Save the Children country report on Nepal 2000.

# 10. Point of Contact:

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