

Moving Ahead for Designing the Future:

Schooling of Nepali Children with Neurological Disorders



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Foreword

It is my great pleasure to present this valuable study report exclusively focused to children with neurological disorder (including cerebral palsy) in schools. SGCP/Nepal in the recent years have integrated over 200 children with neurological disorders with untiring and concerted efforts of parents, community members, school team and SGCP worker in the disability field. Since the integration of children with disability is not an ends, further explorations in creating better learning environment in schools is a constant need. In this line of thought SGCP/Nepal carried out a study to understand problems encountered as well as opportunities available in the process of education of these marginalized children. The present study found that these children are much more committed in study and thus their retention in school was quite high. The study team constituted for this study is able to find much more exhilarating finding, which are valuable for parents, schools, community members, persons and organizations involved in the education and rehabilitation of children with neurological disorder. I find these findings are equally helpful for policy makers and donors.

I urge that all the education planners and implementing agencies and persons give due recognition to the report and pursue its recommendations.

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Executive Summary

Nepal has given very high priority to expand educational access in the country. Given such priority, 95 per cent of primary age group children are now enrolled in school. This very impressive achievement just in 60 years of modern schooling in Nepal which began from almost ground level however has not been equitable. Among total primary children, the proportion of children with disability is only about one per cent while the proportion of disabled in the total national population in the country is said to be between seven to ten per cent. This shows how deprived are disabled in getting educational service. The situation of children with neurological disorder is further worse.

In such a context, this study was carried out with the objective of exploring the educational status of all those children with neurological disorder (ND) who were enrolled in school with the initiation of Self-Help Group for Cerebral Palsy, Nepal (SGCP). SGCP is a non-government, non-profit organization, established in 1986 in Nepal with the main objective of supporting children with cerebral palsy (CP), a neurological disorder (ND). It supports those children by providing medical and psychological assessments, counselling, physical and speech therapy and medicinal, educational, and stimulative services. It also provides emotional and practical supports to the parents/family of ND children through counselling on caring and supporting such children.

One of the objectives of SGCP is to integrate (enrol) children with ND in normal schools. In its four years' efforts 208 children were enrolled in normal schools. This research was initiated with the questions like: were they still in schools or dropped out? How were they performing (or performed)? Could they learn something and did that contribute to improve their

life? The additional concerns of the research were to explore reasons for dropout, available supports, hindering constraints, and perceived benefits.

The study was designed in three concurrent phases – tracing, detailing and qualitative – collecting numeric, narrative and observational data through interview (structured and open), observation and group discussion and using nine different tools. A research team of six independent and experienced researchers carried out this research. The field work was carried out by the SGCP Home Visitors. They were trained, supported and supervised by the research team members.

The study was carried out in 13 districts spread across the country and where SGCP was providing its services. Altogether 604 people participated in this research and they were 177 ND children (continuing and dropout), 93 parents, 196 teachers, 96 peers of ND children and 42 community people. They participated either through structured or open interviews or open group discussion. Among total respondents 266 (44%) were female and 338 (56%) were male. The study also observed 15 schools and at least one class in each of these schools. Likewise, 15 school going ND children were also observed. Narrative data analysis was carried out through a process of coding, categorizing and identifying themes and numeric data was analyzed using SPSS. Conceptual framework for this study was derived from the concept right to education.

Among 208 enrolled children only 177 (85%) could be traced. Due to non-reporting, the study team could not know about the status of the rest 15 per cent. Among traced children, 157 (89%) were still in school and only 39 per cent were girls, the rest being boys. Gender wise, 93 per cent of girls and 85 per cent of boys were continuing. Among continuing children, about three-fourth were in pre-primary or primary levels, their average school year was less than four years (girls 4.4, boys 3.4) and about 43 per cent of them were in age group 9-14. These findings

show that there was very high retention among ND children. This also shows theirs as well as their parents' continued interest towards education. Gender disparity against girls in accessing schooling was clear but once they got enter into the school, more of them retain and retain longer. Likewise, it can also be said that ND children's schooling is a recent phenomenon and that they are late starter.

Reasons for dropout could be categorized as school related, child related and home related. Home related reasons included difficulty to commute to school, distance to school, problems of escorting and accompanying, inadequate help from the family, and economic problems. Likewise, ND unaware teachers, lack of appropriate physical facilities, lack of care, attention and support in school, violence in school (punishment and abuse) by teachers and abuse by peers, safety concerns (unsafe school premises) and no or little learning were main school related reasons and child's own physical and mental situations was the main child related reasons for dropout.

Decision for admission to ND child in a normal school was wholly a parental or family decision. In some cases, Home Visitors from the SGCP had motivated parents to enrol their child in school. Parents were not receiving any other support from any other agency excepting few scholarships from the government and some support from the SGCP itself – mainly in the form of scholarship and some material support. Likewise, excepting very few cases, schools were also not getting any support from any other agency. These realities tell that the schooling of ND children has been a neglected reality in Nepal and even the government was doing nothing in this regard.

It was found that even getting admission into a school could be problematic for some ND children and their parents. Some schools were found trying to avoid those children mainly

because of lack of facility in the school and also because of lack of support from anywhere. It was also found that in some cases some teachers and parents of some other children did not want to see ND children in school simply because of misinformation about ND. There was thus a situation of no or little support for the schooling of ND children and some schools/parents were even showing indifferent behaviour towards those children.

Classroom and school environment was not ND child-friendly because the classrooms were crowded, there were no appropriate seating, and pathways and premises were not safe. Likewise, drinking water and toilet facilities were not appropriate for ND children. However, few schools were found with facilities appropriate for ND children, constructed with the support from the SGCP. Moreover, teachers were following conventional modes of teaching and there was no preferential treatment for ND children. All these were good reasons to prompt for dropout. Some teachers and peers were however praised for their supportive and loving behaviour. Similarly, ND children were generally attentive, participating in the class and friendly towards teachers and peers. Majority of their emotional and health conditions were reported as normal. They were getting good care and support in their home.

Parents reported many benefits of schooling or positive changes in ND children after schooling. These included improved self-dependency, improved reading and writing and intellectual and physical capability, can converse well, started to play, developed study habit, remained disciplined, wanted to stay neat and clean, has shown some creative thinking and practices, etc. Most parents were realistic in the sense that they were not expecting their ND child to be able to earn their living independently. They were simply expecting that at least their child could become self dependent in their everyday activities like eating, toileting, changing dress, moving around, and could converse well and become socialized. Parents were happy that

schooling was contributing to build these capabilities in their ND child. It was clear that schooling has brought them out of their home-confinement and has given them a wide avenue and exposure to new learning. Opportunity to interact with teachers and peers was more important and beneficial for them than what they could have learned from books and lessons. That is why parents were providing all possible supports to their ND child that included escorting to and from the school, supporting in doing homework, providing materials, creating supportive environment, etc.

Majority of continuing ND children said that they liked going school, were regular in attending the school, and liked their teachers and peers. They think they were very well or average in study and in making friends. Little gender differences were observed in these behaviour and practices. All these findings showed that ND children were accepted and treated normally as other children as well as loved and liked by teachers and peers. This, in turn, showed their commitment and confidence towards their schooling.

Unlike continuing children, dropout children could not maintain their commitment towards their schooling though they also liked going to school and were regular in attending the school. Most of them think they were average or low in study, sports and in making friends. However, some of them complained about not getting opportunities in aspects like sports illustrating negation and humiliation they faced while in school. Most of them were doing nothing after dropout and were thus in bleak future prospects. They did not like scolding, disgrace and ignoring from the family/parents and hating and discrimination from others. Most of them were (semi)independent in eating, toileting, going out, reading-writing. The lack of support in schooling of ND children could be illustrated from the fact that those children who wanted to go to school, who were regular in going school, and who were mostly independent in

their everyday activities had to dropout from their school. Though dropout ND children liked their school and teachers and peers, half of them did not like the idea of reenrolling in school. This was mainly because the reasons due to which they had to dropout were still there. That is, unless the problems of dropout were addressed there was no or little use of making additional efforts.

One problem associated with schooling of ND children was the negligence of doing physical therapy regularly. Regular therapy was very essential for ND children to maintain and improve their mental and physical status. But it was found that many of these children (both continuing and dropout) were not doing therapy in a regular manner. This showed the need for continuous support and counseling.

Teachers were of opinion that ND children were regular, interested/capable in study and in making good relations with others. However, while majority of children see themselves as better in their school performance teachers see them only as average. It was found that one-fifth of teachers see ND children better in their academic excellence and two-third see them as average. One very critical reality related to teachers was that most of them have little knowledge and understanding on ND and they had no training/orientation on ND at all. Teachers accepted that they have been using same conventional methods of lecturing and they do not use any special strategy/methods to teach ND children. Majority of teachers have recommended for establishing special schools for these children. Teachers had no idea if there were any government programs and policies to support the education of ND children.

It was found that community people and peers had no or little idea on ND. However, they accepted ND children as normal and behaved and interacted with them in a normal manner. Some peers noted helping ND children in different activities like in study, doing homework,

toileting, eating, etc. There were some people as well who were taking ND as a sin of previous life.

One critical reality illustrated by the present research was the sheer denial of right to education to ND children. Among 50-70 thousands estimated Cerebral Palsy children in Nepal, less than one per cent was getting access to school. This showed how severe was the situation. Among those who were enrolled had also faced denial on many different sense. Getting admission was not easy for them and many faced discrimination and denial. Aspects of right to education like availability, accessibility, acceptability and adaptability were meaningless for them who were forced to drop out from the school. Many of those who were still within the education system were facing abusive behaviours like discrimination, punishments, and bullying and many of them were facing violation of their right not only in the school but also within their home. Their right was being violated by the state, the society and by the family. It was the obligation of the government to ensure the right of the ND people and it was the responsibility of the society as well as of the family to ensure such right. The reality was that the government was failing to fulfil its national and international commitments. Likewise, the society and the family were also failing to honour their obligations.

However, some of the ND children were fortunate to access the school. Most of them were very committed and capable to carry on their schooling and that their schooling has contributed for a very positive outcome or benefits on their part. The schooling has provided them the opportunity to interact with their teachers and children and thus for wider exposure for learning new things. They were learning more from such interaction and exposure than from their lessons and books. Their family has supported them very well in their schooling but very

unfortunately they were not getting any support from any other agencies, even from the government.

Recommendations

Following recommendations are made so that the educational opportunity of ND children could be improved and their right to education could be ensured:

- *Right to education.* Developing a system where the government honors its national and international commitments of ensuring right to education of ND children is essential.
- *Legal framework.* Developing legal framework is necessary to bind government agencies as well as political bodies at all levels (regional and local governments/bodies) towards ensuring right to education of ND children.
- *Local bodies' role.* A deliberation is essential on the role of local bodies in addressing the concerns of educating ND children. Actually, educating ND children could come under the jurisdiction of local bodies but they should be supported by the government.
- *Data system.* A comprehensive information system is prerequisite for a successful planning exercise. Hence, it is necessary that the government develop a data system related to ND or include ND component in existing data system.
- *Integration in normal school.* This research has shown that the opportunity to interact with teachers and other normal children could be very important in the learning and development of ND children. Hence, possibilities could be explored of developing especial educational programs (run in normal class/schools) for ND children where they get preferential treatment.

- *Special schools or annex unit in normal schools.* Depending upon the intensity of ND situation in particular children, special schools might be needed for them or where appropriate, special annex unit could also be established in normal schools.
- *NGO network.* The government might motivate prospective NGOs to work in the area of providing educational access to ND children and support these NGOs. A network could be developed of such NGOs.
- *Collaboration in approach.* Collaboration among the government, local bodies and the SGCP is important in diagnosing and remedying the educational needs of ND children. Local NGOs/clubs/groups/individuals' support could be important in such collaboration.
- *Teacher training.* It is essential that school teachers be provided some training or orientation on different aspects of ND and on teaching and behaving them. The SGCP could support in designing and delivering such training/orientation.
- *Orientation on ND to different other people.* It is also essential that orientation be provided to different other stakeholders particularly parents and peers at school and others including community people about ND and its different aspects. The government and the SGCP could collaborate in carrying out such exercise.
- *Physical environment.* Making physical facilities in school as per the need of ND children is essential in order to ensure their right to education or in order to facilitate their active participation in school processes.

Following two recommendations are specifically for the SGCP

- *Advocacy.* SGCP could develop a system of advocacy programs for ensuring the right to education for all school age ND children in the country encompassing all educational

stakeholders including the government, parents, schools, local bodies, community people, and other organization, groups and individuals.

- *Education service.* SGCP needs to expand its educational service to ND children. This could include identifying out-of- school ND cases, making efforts to send them to school, and following-up schooled ND children and their participation in learning and other school processes.