

Self Help Group for Cerebral Palsy (SGCP)

Moving Ahead for designing the future:
Schooling of Nepali children with neurological disorders

A research report

1 March 2012

Kathmandu, Nepal

ND in Nepal - an educational concern

- ❑ One of the objectives of SGCP - integrate (enrol) children with ND in normal schools
- ❑ So far, 208 children in schools - a four years effort of SGCP, some parents have also enrolled their children individually
- ❑ Estimated ND children in Nepal: 50-70,000
- ❑ Huge gap between "need to be served" and "served"

The present research

- ❑ Once enrolled, no functional relationship with the child; that is, SGCP does not know **much**
 - ❑ where are those children who were once enrolled in schools?
 - ❑ are they still in schools or dropped out?
 - ❑ how are they performing (or performed)?
 - ❑ could they learn something and did that contribute to improve their life?

The research questions

- ❑ These questions gave rise to this research
- ❑ The additional research questions were
 - ❑ why some are still in school and some not?
 - ❑ what supports/constraints are there?
 - ❑ how the schooled ND children and their parents see the benefits of schooling?
 - ❑ are they maintaining therapeutic exercises?
 - ❑ are there any interventions from the govt?

The design of the research

- ❑ A very elaborate design
- ❑ Three concurrent phases - tracing, detailing and qualitative
- ❑ Collecting numeric, narrative and observational data with nine different tools
- ❑ Interview (structured and open), observation and group discussion
- ❑ A research team of six people; SGCP Home Visitors contributed as enumerators

The design of the research

- ❑ 13 SGCP districts (out of 16)
 - ❑ (one was not included in the study and no forms could be obtained from two districts)
- ❑ ND children (continuing and dropout), their parents, teachers, peers and community people
- ❑ Out of 208 enrolled ND children, only 177 (85%) could be traced
 - ❑ (three missing districts)

The design of the research

- A total of 604 participants:
 - ND children - 177, parents - 93, teachers - 196, community people - 42, child peers - 96
 - Continuing ND child - 157, dropout - 20
 - Tracing -354, detailing -369, qualitative - 20 (this is more than 604 because of repeat)
 - Female - 266 (44.0%), male - 338 (56%)
 - Observed school/class - 15 (7+3+5)

The design of the research

- Observed ND children - 15
- Piloting and supervision of field work
- Narrative data analysis - a process of coding, categorizing and identifying theme
- Numeric data analysis - SPSS
- Conceptual framework for this study - Child Rights, and Right to Education

Rationales for this research

- ❑ Build a knowledge base on educational/schooling of a particular group of children
- ❑ Advocacy, awareness building, policy/program development for establishing their rights
- ❑ Important in the context of national commitment on child rights and on EFA
- ❑ Rationale for the SGCP itself
- ❑ Rational for the government, other agencies

ND children at school: Retention/dropout

- ❑ Total enrolment - 177
 - ❑ girls - 69 (39%), boys - 108 (61%)
 - ❑ gender disparity, discrimination
- ❑ Continuing - 157 (88.7%) - very high retention
- ❑ 94% girls are continuing, boys - only 85%
- ❑ High retention among girls
- ❑ Girls get less access to school but if they get, more of them retain

ND children at school: Retention/dropout

- ❑ ND children are late starter - 43% of continuing children are in age group 9-14
- ❑ Schooling of ND children a recent phenomenon - 42% have the school life of less than two yrs and mean years in school - 3.8 yrs
- ❑ Girls stay longer in school -
 - ❑ mean years in school: girls - 4.4, boys -3.4
- ❑ More of girls retain in school and retain longer

ND children at school: Retention/dropout

- ❑ Enrolment by level (N=157)
 - ❑ Pre-primary - 21%
 - ❑ Primary - 54%,
 - ❑ Low second - 18%,
 - ❑ Secondary - 5%
 - ❑ High second - 2%
- ❑ SGCP began its schooling program 4 yrs ago, some parents have sent children on their own

Causes of dropout

Causes	Dropout ND children (N=20)		Parents of dropout ND children (N=20)	
	Number	%	Number	%
Punishment/abuse	7	35.0	4	20.0
Difficulty to commute school	3	15.0	6	30.0
Distance to school	6	30.0	9	45.0
Inadequate physical facilities	6	30.0	11	55.0
Economic problem	6	30.0	10	50.0
Health problem	12	60.0	14	70.0
Inadequate help from the family	10	50.0	9	45.0

Causes of dropout

- ❑ Reasons for dropout-home, school, child, related
- ❑ Home related reasons
 - ❑ difficulty to commute to school
 - ❑ distance to school
 - ❑ inadequate help from the family
 - ❑ problems of escorting and accompanying
 - ❑ economic problems

Causes of dropout

- ❑ School related reasons
 - ❑ 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)
 - ❑ no or little learning

Causes of dropout

- ❑ Child related: mental and physical problems
 - ❑ no or little learning
- ❑ *"I myself became an obstacle. My dear mother who has done so much in my life couldn't carry my bulky body in her old age."*
- ❑ A twelve year old child is placed in *shishu kaksha* - *"If she was placed with bigger children she would then love to go there."*

Causes of dropout

- ❑ *"I pulled out my child from school because there was no difference at all; he had not learned anything from his school."*
- ❑ *"I am not going to school again. Everybody tease me, laugh at me and pull my hair."*
- ❑ *"I did not like my Miss. She often would snatch my note book and would beat me with a cane when I was not able to write fast in my notebook."*

Education environment - school and home

- ❑ Admission - Home Visitor's counseling and parents' decision to admit
- ❑ Some cases of problems in getting admission
- ❑ Indifferent and unjust behavior towards ND children (by some schools and some people)
- ❑ No support from the system, indifferent behavior of the people/school

Education environment - school and home

- ❑ Classroom and school environment - not ND child-friendly
 - ❑ crowded classrooms, not appropriate seating, unsafe pathways and premise, inappropriate drinking water and toilet facilities
 - ❑ unsupportive teachers and peers
 - ❑ conventional mode of teaching
 - ❑ lacking preferential treatment

Education environment - school and home

- ❑ All these would prompt for dropout
- ❑ Some teachers and peers were however praised for their supportive and loving behavior
- ❑ ND children however were generally attentive, normal, participating in the class, and friendly towards teachers and peers
- ❑ Health and emotional conditions - normal
- ❑ Good family care and support

Benefits from the schooling

Benefits	Parents of continuing ND children (N=45)	%
Has become self-dependent	36	80.0
Has improved intellectual and physical capability	41	91.1
Can converse well	40	88.9
Can read and write	45	100.0
Can earn money in the future	3	6.7

Positive changes after schooling

- ❑ Started to play, developed study habit, remained disciplined, wanted to stay neat and clean and were showing some creative thinking and practices
- ❑ *"She is changed. She has learned many new things and can now manage herself."*
- ❑ *"She is now able to make friends, get education and get love and affection from her teachers."*

Support for schooling

- ❑ Supporting agency/person (N=45 parents)
 - ❑ 41 (91%) mentioned family
 - ❑ 23 (51%) school
 - ❑ 9 (20%) other agencies
- ❑ Support from school -
 - ❑ learning, socialization, developing some habits (toileting, being hygienic, liking and participating sports, etc)

Support for schooling

- ❑ Support from other agencies -
 - ❑ only 9 were getting some support
 - ❑ among them, 6 were getting from the SGCP
 - ❑ some also from more than one
- ❑ Educational, material and medicinal support
- ❑ That is, ND children and their education has largely remained an ignored reality in Nepal, even the government was doing nothing

Support for schooling

- ❑ Family support
 - ❑ Escorting to and from the school
 - ❑ Supporting for the homework
 - ❑ Supporting in the daily activities of the child
 - ❑ Managing materials
- ❑ No more therapy after joining the school
- ❑ Parents were however aware on the need for therapy (but not practicing)

Dropout children

- ❑ Average or not so good in performance and involvement in activities at the school
- ❑ Constraining factors - lack of ND aware teachers and drinking water, toilet facilities
- ❑ Bleak future prospect of these children
- ❑ Possibility of resending dropout children to school was expressed as high by their parents but constraining factors are to be addressed

Perceptions of continuing children

- ❑ Most of 157 continuing children said they like going school and are regular
- ❑ Most of them think they are very well or average in study, sports, and in making friends
- ❑ Most of them like their teachers and friends
- ❑ They are accepted/treated as equal to other children, loved/liked by teachers/peers
- ❑ Show their commitment and confidence

Perceptions of continuing children

- ❑ Some aspects of the school they do not like
 - ❑ physical facilities (drinking water and toilet)
 - ❑ Some girls and boys also mentioned about abuse and punishment
- ❑ Not a very pronounced gender differences except in few areas (liking sports)
 - ❑ boys were more complaining
 - ❑ more girls complained about toilet

Perceptions of dropout children

- ❑ Dropout children (20) said they were also interested to go to school and were regular
- ❑ Most of them think they were average or low in study, sports and in making friends
- ❑ Liked teachers/peers; did not like facilities
- ❑ Complained about not getting opportunities in aspects like sports
- ❑ Illustrates negation and humiliation they faced

Perceptions of dropout children

- ❑ Doing nothing after dropout
- ❑ 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
- ❑ Half of them did not like reenrolling in school

Perceptions of teachers

- ❑ ND children were regular, interested/capable in study and in making good relations
- ❑ Children see themselves 'better' but teachers see them 'average'
 - ❑ illustrates teachers' tendency of seeing them 'normal' like others
- ❑ learning achievement of ND children (N=151):
 - ❑ 20% - very good, 64% - average

Perceptions of teachers

- ❑ Among 45 teachers in detailing phase,
 - ❑ 15 have some idea on ND
 - ❑ 5 have some training on children's inability
 - ❑ 13 said getting some support from the SGCP
 - ❑ 4 noted some support from the DEO
- ❑ *"We teach them as other children, no difference."*
- ❑ *"We have not taken any special training to teach and care them."*

Findings of the study

- ❑ Despite acceptance of child rights and right to education, government has done nothing for ND children
- ❑ A huge gap between *commitment* and *reality*
- ❑ Almost all ND children are discriminated
- ❑ Whatever education few ND children have got, was made possible by parental efforts
- ❑ Some of them were supported by the SGCP

Findings of the study

- ❑ Very high retention: those who were enrolled most (89%) were still in schools
 - ❑ showed willingness and commitment of ND children/parents to continue, learn something - most important factors for high retention
- ❑ Teachers and peers support - important to remain in school

Findings of the study

- ❑ Some of the main constraints in ND children's schooling: difficulty to commute to school, their own mental and physical problems, poor physical facilities, abuse, lack of preferential treatment, poor economy of the family
- ❑ Girls were discriminated in accessing school but once entered, more of them stayed and stayed longer

Findings of the study

- ❑ Excepting few, their performance in school was *average to good*, children themselves saw them *good*, while teachers described them *average*
- ❑ Parents and children themselves see lots of positive improvements in them - confidence, communication, independence, cognitive skills
- ❑ Some positive changes in everyday life pattern and also some future prospects

Findings of the study

- ❑ Practice of therapeutic exercise was not very regular for many ND children, though commuting to and from school has contributed for movement of their bodily motors
- ❑ Dropout children have remained in home doing nothing, staying idle
 - ❑ not interested in re-enrolment in schools
 - ❑ thus, with very bleak future prospects

Some recommendations

- ❑ Right to education - Government honor its national and international commitments
- ❑ Invest in educating ND children
- ❑ Legal framework - necessary to bind government as well political bodies at all levels
- ❑ Local bodies' role -
- ❑ Data system - as prerequisite
- ❑ Integration in normal school

Some recommendations

- ❑ Special schools or annex unit in normal school
- ❑ NGO network - motivating them and working with them
- ❑ Collaboration in approach - working together
- ❑ Awareness building - teachers, students, parents on ND children and their needs
- ❑ Work for developing ND children friendly physical and teaching learning environment

Some recommendations

- ❑ SGCP - advocacy and service
 - ❑ expand its educational programs
 - ❑ work with government, DPs, NGOs, clubs, groups, individuals for
 - ❑ sending more ND children to school
 - ❑ increasing teachers' awareness on ND, their learning needs and delivery strategy
 - ❑ mobilizing local community club for assisting in ND children's schooling