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

<table>
<thead>
<tr>
<th>Causes</th>
<th>Dropout ND children (N=20)</th>
<th>Parents of dropout ND children (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Punishment/abuse</td>
<td>7</td>
<td>35.0</td>
</tr>
<tr>
<td>Difficulty to commute school</td>
<td>3</td>
<td>15.0</td>
</tr>
<tr>
<td>Distance to school</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>Inadequate physical facilities</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>Economic problem</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>Health problem</td>
<td>12</td>
<td>60.0</td>
</tr>
<tr>
<td>Inadequate help from the family</td>
<td>10</td>
<td>50.0</td>
</tr>
</tbody>
</table>
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

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