

Serving Children with Cerebral Palsy

An Appeal for Support



Self-help Group for Cerebral Palsy

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1. Introduction

Self-help Group for Cerebral Palsy (SGCP), which is popularly known as CP- Centre, is a non-governmental and non-profit organization established 21 years ago in Kathmandu, Nepal, is serving children with cerebral palsy. The main objective of the organization is to provide care, comfort and relief to the children and adults with Cerebral Palsy (CP) through various interventions. In line with its objective SGCP runs a rehabilitation centre and special education programme as well as home based support programme to children with cerebral palsy and their parents. Being the only organization in Nepal, which is exclusively dedicated in the rehabilitation of children with cerebral palsy, SGCP collaborates with partner organizations and agencies through various means and approaches to attend and benefit the CP cases through out the country. SGCP is an Associate Organization of The International Cerebral Palsy Society, London.

The **CP Rehabilitation Centre** of SGCP is located in the Kathmandu valley and provides counseling services, therapeutic services, medical services, training of parents as well as training of field workers from various organizations in the field of rehabilitation of children with cp. Physiotherapists, occupational therapists, councilors, and pediatricians are engaged in the centre. The centre provides support to over 400 cp cases annually.

Special Education Programme for children with cp was launched in 1992. As far as possible they are integrated in normal schools or send for income generating activities after they have acquired required knowledge and skills through special education programme of SGCP. In

Cerebral Palsy is a childhood disability condition caused by brain impairment done due to pregnancy complications and birth trauma. This condition is marked by spasticity involuntary movements and posture and movement problems which are often accompanied by associated handicaps. The severity of a cp case depends on the intensity of the brain damage; and the condition gets complex if associated by epelepsy and learning disabilities. Without early intervention, cp cases suffer a great deal life long. In Nepal, this target group is much neglected and their plight is almost beyond description. It is more so in the rural sector of the country. Cerebral Palsy situation in Nepal is a genuine case of "hidden catastrophe" as little is done at the national level for its prevention and for the rehabilitation of children with it.

this programme there are classes with total capacity of 36 children at the moment.

Since not all children with cp can be enrolled in its limited class capacity, SGCP has recently started home based schooling of children in which parents as well take active role in the teaching learning process. This programme, as of its difficult nature, is at present limited to Kathmandu Valley only. However, SGCP is encouraging other non-governmental organization to initiate special education in other parts of the country. In this effort the organization has successfully helped a NGO to run such centre in the western part of the country (Pokhara).

Home Visit is one another successful programme of SGCP, which is run under **Out Reach Programme**. In this programme a home visitor helps children with cp by visiting their respective homes. This programme is discussed in details in the following paragraph (**para 2**) and which is also central to this proposal.

Currently, SGCP is operating with 49 full time staff and 5 part time professionals. It has acquired its own land where a rehabilitation building has been recently constructed. The building has become fully operational since March 2006. SGCP is now planning to construct a school building for children with cerebral palsy.

Apart from the local level support several donors from abroad is supporting SGCP activities. Some of the donors with their major area of focus are given in the following Table 1:

Table: 1 Name of Donors

	Supporting agencies/individuals	Major Focus
1	Lillian Fond, Holland	Special Education Programme
2	Stichting Holland Building, Holland	Infrastructure
3	Bob and Frances Corraza, Ireland	Infrastructure,
4	Lionø Club, Germany	Salary support of professional staff, training of staff, equipment and materials.
5	Saraswati Foundation, Switzerland	Special Education Programme
6	Siddhartha Foundation, Germany	Out Reach Programme in three districts
7	German Nepalese Help Association, Germany	Out-Reach Programme in eleven districts
8	W.P. Schmitz-Stiftung, Germany	Out-Reach Programme in two districts
9	Nepal Projektfoerderung e.v, Germany	CP Rehabilitation Centre

2. Out-Reach Programme

2.1 Introduction

SGCP is Kathmandu based, however, its services are extended to 15 districts (of the total 75 districts of the country) through **Out-Reach Programmes (ORP)**. **ORP** was initiated in 1998 as the widespread of the CP cases were noticed across the country. Under this programme, specially trained **Home Visitor** provide services to CP cases by visiting their respective homes. At present, 15 home visitors are engaged under ORP and helping over 500 children with cp and their parents annually.

During the home visits CP children receive therapy exercises. Similarly, parents are provided with counseling and instructions to continue the therapy. The home visitors also develop equipment and assistive devices from locally available materials to support the children with cp. When needed parents are also advised to take their children to rehabilitation centre. In general, one home visitor serves over 30 cases a year. They also work in collaboration with local NGOs and GOs, especially with health related organizations (see **Annex I** for Job Descriptions of Home Visitors).

2.2 Home Visitors:

The candidates for home-visitorsøposition are selected from the respective district and trained for a period of six months. On the successful completion of this training, they are given appointments. The training curriculum consists of the basics of therapies essential for communication, ADL (Activities of Daily Living) and physical disabilities along with the concepts and techniques related with cp and its rehabilitation processes.

On-theóspot training is also provided and opportunity for experience sharing is given for every home visitors.

2.3 Self-help Group at local level

Recently, self-help group of parents at local level were formed as a trial basis in two districts. The main purpose of this group is to enhance the services to children with cp at local level. It is believed that such groups will prove to be sustainable to continue the support system. Home Visitor performs the role of a facilitator in this parents group. Within a short period of six months existence of these parents groups they have demonstrated active involvement for the benefit of children with cp and their parents. They have organized cp assessment camps and established moral support to parents of children with cp. These groups also supported work of the home visitor to bring efficiency as well as effectiveness in the service. Much

needed local supports to home visitors are being met through these groups. Since such self-help groups of parents are already showing positive impact, SGCP looks forward to create such groups in other remaining ORP districts as well.

2.4 Budget

Currently, the funds spend to run ORP in a single district comes around Euro 1600 per annum. This covers salary of one home visitor, supervision and reporting, stationeries. Extra funds are sought from elsewhere for training, equipments and toys.

3 ORP experience

Over the years of experience on ORP implementation it is found quite effective despite there are working difficulties that are related with low/no education of parents, their poverty stricken situation and the lack of professional and institutional support. The strategy of door-to-door support through home visitors is the right one for providing early intervention and meeting the special needs of children with cp. Besides these, in conformity with the nature of cerebral palsy which has no cure and which warrants long term care and support, the active involvement of the parents in the rehabilitation process, ORP is the right approach. The parents- professional bonding that is implicit in the ORP approach is so much useful for early intervention for making the parents less dependent on the therapists and for awareness building about cerebral palsy in the community. This approach is equally useful for providing education to children with cp who has limited physical mobility. Best of all, it has contributed much for improving the quality of life of the children and their parents. Thus ORP as an effective strategy and approach for CP Rehabilitation in the rural sector deserves consolidation and expansion in many districts of Nepal.

(See attached two brief field reports of volunteers for their observations and impressions Annex II)

4 The Problems confronted with

In view of effectiveness of the Out Reach Programme, SGCP is not being able to expand this programme to more districts and locations simply because of lack of funds. The problem is ever more compounded because some of the donors have funding problem. This was the case with German Nepalese Help Association (GNHA), which is funding for 11 districts. The GNHA, though very much convinced of the genuine worth of ORP, has, in advance, informed their inability to support the annual running cost of NPR 1.6 millions (Euro 18,000) required for 11 districts. Similarly, projects with W.P. Schmitz-Stiftung funding is nearing completion. So it is now essential for SGCP to seek for funding to continue as well as to expand the ORP to new districts and to new locations. It is well understood that lack of funds will directly affect over 500 children with cerebral palsy.



Phanchkhal Valley: Work station of a Home Visitor



Self-help Group of parents in Sindhupalchowk poses with the Out Reach Programme Incharge (standing with briefcase and the Home Visitor (sitting in cap).

The Proposal

For giving continuity with such an effective programme like ORP in the present programme districts as well as to some new districts, SGCP proposes for required funds from generous and interested donors. SGCP urges to give priority to 12 districts supported by GNHA and W.P. Schmitz-Stiftung. Names of the districts are given below in Table 2.

Table: 2 Out-Reach Programme Districts

S.No	Name	Region	Funding Agency
1	Dadeldhura	Far Development West Region	German Nepalese Help Association, Germany
2	Doti	õ	õ/ closed
3	Kanchanpur	õ	õ/closed
4	Dang	Mid West Development Region	õ
5	Kapilbastu	Western Development Region	õ
6	Butwal, Rupandihi	õ	õ
7	Tanahu	õ	õ
8	Makawanpur	Central Development Region	õ
9	Kavre	õ	õ
10	Sindhupalchok	õ	õ
11	Ramechhap	õ	õ
12	Taplejung	Eastern Development Region	W.P. Schmitz-Stiftung, Germany
13	Kathmandu valley (3 districts)	Central Development Region	Siddhartha Foundation, Germany

Upon the continuation of ORP in above districts, SGCP ventures to run the programme in another 5 more districts. These new districts will be selected from Tarai (Plains) and mountain regions of the country.

Funding required

It is estimated that Euro 1650 per year will be required for ORP in a single district (details in **Annex III**). That means total funds required for 20 districts for

five years is estimated at Euro 165,000. Following table 3 shows budget calculation,

Table: 3 Budget estimates for ORP (in Euro)

	Year1 (2007)	Year 2 (2008)	Year 3 (2009)	Year 4 (2010)	Year 5 (2011)	Total 5 years
Budget for 20 districts	28520	32660	33580	34500	35460	164720

The Appeal

SGCP requests interested individuals and institutes to support for the cause of rehabilitation of children with cerebral palsy partly or fully covering the cost of Out-Reach Programme.

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Job Description: ORP Home Visitors

- To find out cp cases with the help of persons from-
 - VDC
 - Health/ Hospital
 - Teacher
 - Social services minded persons
 - Local organization involved in disability.

- To assess the case and prepare the treatment plan.
- To teach different therapeutic exercises and techniques to the parents.
- To do the following in the follow-up visits-
 - To assess the cases whether there have been some improvement in the case concerned.
 - To check whether exercises given by the parents are complete and correct and to give correction and when necessary through demonstration.
 - To teach new exercises and new stimulation techniques to parents and when necessary.
 - To develop rapport with the children and the parents so that interaction with them will be facilitated.
 - To refer cases to CPRC as necessary
 - To counsel the parents on different aspects of cp and the importance of maintaining general health of the cases as necessary.
 - To give suggestions for the use of simple aids for the cases.

- To maintain records of the home visits under the following heads-
 - General contrition of the case (improving/not changed/ deteriorating)
 - Quality of life of the child (getting better or not getting better)
 - problems found and things taught.

- To send fortnightly forms of the home visits duly completed to the Centre Office.
- To come to the centre when called by the Centre Office for sharing field experiences and sorting out problems.

- To cooperate to the physiotherapist and other personnels sent for field supervision from the Centre Office
- To submit travel document (bus tickets) to the administration assistant for claiming TA.
- To take measurement of the special chairs and postural aids if cases need them.
- To do other things as directed by the Executive Director.

Annex II a

Report of Out Reach Programme in Kapilbastu District

by
Ingrid Kirsch, kirschhain@gmx.de
 Germany, Volunteered at SGCP,
 September-December 2006

1. Children I visited and comments:

Ajuss:

Still crying a lot; not interested in anything; no exploring; didn't enjoy proprioceptive stimulation either like sliding and swinging in a hammock.

Parents are giving too much support and they take him up immediately when he starts to cry. Because his crying is sometimes automatically it might be important to make him find out what to with himself by not always taking him on the lab.

Sabin:

Is very motivated and intelligent; sometimes seems to have problems with his eyes, did his eyes ever get tested? should get less support by the transfers; he should learn to stand up by himself by holding on to the couch.

His standing abilities are getting much better when he is standing in front of the table and does some painting or playing

Because his mother doesn't speak any English this might be recommended to her by Shankar. A simple standing frame might also be helpful for Sabin.

Chhering:

No hand function and also deformed upper palate (no writing or painting was possible with his mouth)

Good mental condition; doesn't go to school because he is not able to sit in his special chair and wouldn't stand the bus ride due to his contracture of the left leg. In my opinion going to school would be very good for him. Even without an operation of the leg he should practice to sit in his special chair. While sitting he should not get forced to extend the left leg.

Because the mother doesn't speak much English Shankar might do some counseling about this issue.

Leeza:

Her mother wants her to use a computer; she regards the computer as an interesting toy and likes to play with it but doesn't use it in any meaningful way. Due to her attitude and her poor hand-functions getting a computer doesn't seem very useful. A "children's computer" with big buttons might be nice for her.

Erean:

The contracture of his left leg is sometimes very painful during sitting. An operation of the leg might be considered.

Because of his blindness and his poor hand-functions it is difficult to make him assist with the ADLs and to make him play.

His parents are taking very good care of him.

Prabess:

Because of his blindness and his severe mental retardation it is very difficult to improve his life. His parents are also taking good care of him.

Ajusha:

Severe mental retardation; doesn't show any interests; feeding is difficult.

Should stand sometimes in front of the window to improve the nutrition of her lower bones. A special chair would be useful for her to make her participate more.

Sanjana:

Because of the persisting ATNR it is very difficult for her to do anything.

A table for the special chair she already has might be useful.

2. General comments:

Although some of the parents speak English and some exercises and positioning-possibilities can be shown without being able to talk a lot it has been a big problem that I don't speak much Nepali. To me it has been a very interesting experience and huge challenge. In my opinion Shankar has a very good approach in counseling the parents and providing very helpful advices to the relatives.

I think additionally it could be nice to use more often toys for the home visits, because some families don't have any or only a very few toys at their homes. The toys could be used to find out what kind of games the child is interested in and if a different position makes it easier or harder for the child to play. Also it sometimes might be important to show the parents how to play at all.

e.g. when Sabin is standing in front of the couch he is able to hold himself. If he is playing with a car and he makes the car drive down a ramp he is able to stand for a long time while playing and enjoys it. While putting the car back on the top of the ramp he shows a very nice extension and stability of his trunk.

Conclusion:

I am very glad to have had the opportunity to work with the CP-Center. I learnt a lot from my colleagues and from the children.

Special thanks to Suresh for his excellent organization of the ORP and the HVP, thanks to Shankar for his very nice introduction of the children and the families and thanks also to all the others for the great time I had.

Annex II b

Report of Out Reach Programme in Jhapa District

by

Sandra Degenherdt
Germany, Volunteered at SGCP,
September-December 2006

Location of visit: Jhapa; Damak Date of visit: 06.11.-13.11.2006
SGCP Home-Visitor: Mrs. Kalpana Baral

Children we visited and comments:

Tulasa Shresta:

She is very happy with her laptop and uses it every day (mainly to play games)

Susma Maji:

Got a scholarship to go to school, no clear speaking, good writing

Padam Demsina:

Very thin, likes to ride his bicycle

Bissu Bazerverarai:

Spends the whole day alone at home in front of the television

Nimaya Bhujel:

Does a special training to do handicrafts

Chendrakala Subede:

Totally independent in all ADLs, no severe hemiplegia.

She is getting too much support by her family

Binod Neubangi:

Got a scholarship; his parents built some parallel bars for him to practice his walking. In spite of his athetosis he is very good in stabilizing himself and doing some writing

Pusba and Bobitra Rauth:

Both children might need some special shoes or bandages some day; their mother is giving too much support; children should try to stand and to walk often during the day (may be the parents could build a standing frame or a walker made of bamboo)

Bikram Baral:

His mother doesn't take good care of him (she doesn't want him at all)

Rokwan Mohamod:

Is able to walk with assistance; parents would like to get a wheelchair from the CP-Center; Dr. Gunter and Claudia Gross-Selbeck recommended a bamboo-walker, when they visited the family; the parents didn't realize the walker so far. I am not able to judge about the question, whether a wheelchair is really necessary!

Milan Tamange:

Spends most of the time in the house; is interested in toys and his surrounding; completely depending in all ADLs;

Lives with his grand-parents who are both sick; very poor family;

In my opinion a wheelchair would be a great help for the grandparents and might help Milan to become more socially integrated!

Sugan Nepal:

Should practice his standing-abilities

Amrit Damange:

new case; might need a splint for his left hand

Ganesh Subba:

new case; no CP, but genetic disability

General comments:

The toys the CP-Center provided to the home-visitors are a big enrichment as well as the scholarships. Especially for Binod it is great that he is able to go to school and to improve his good intellectual skills.

Many of the children are pretty old. Because it is very important to counsel the parents of a child with CP as soon as possible, more public relations might be necessary. Maybe some advertisement in hospitals or in other places is possible. By it the counseling could be a bigger benefit for the children when started earlier.

Concerning the parents of children with CP I see a lack of creativity.

e.g.: Sometimes it could be easy to make a child stand while holding the railing or to improvise a simple bandage or splint to stabilize the foot

I also see a lack of simple technical aids (like walkers made of bamboo, standing frames etc)

In my opinion it is an important part of the counseling to encourage the creativity of the parents and to make them try different things and positions with their children. They also should get encouraged to make simple aids. It would be helpful if the home-visitor showed them pictures of aids (very well illustrated in one of the books provided to the home-visitors). If the family is very poor it would be helpful to motivate the family by offering them financial support to pay for the materials they need to make some aids.

Conclusion:

In my opinion more creativity is needed to find better positions and to make simple aids. If the CP-Center were able to provide some additional money to make simple aids, it would be very motivating for very poor families. I think even a very small amount of

money (to buy wood, bamboo, nails etc.) could make a big difference and improve the life of some affected children a lot.

Annex III

Cost Estimate for one ORP District in Euros

Budget No	Budget Head	Year 1 (2007)	Year 2 (2008)	Year 3 (2009)	Year 4 (2010)	Year 5 (2011)	Total of 5 years
1	Personnel Cost						
1.1	Salary	780.00	936.00	960.00	984.00	1,008.00	4668.00
1.2	Contribution to provident fund	78.00	94.00	96.00	98.00	101.00	466.80
1.3	Compensation for Leave	52.00	62.00	64.00	66.00	67.00	311.20
1.4	Festival allowances	65.00	78.00	80.00	82.00	84.00	389.00
1.5	Group insurance	6.00	6.00	6.00	6.00	6.00	30.00
Sub Total 1		981.00	1176.00	1206.00	1236.00	1,266.00	5865.00
2	General Cost						
2.1	Bank charges during transactions	33.00	33.00	33.00	33.00	33.00	165.00
2.2	Telephone/Fax	17.00	17.00	17.00	17.00	17.00	85.00
2.3	Postage/currier	11.00	11.00	11.00	11.00	11.00	55.00
2.4	Stationary	11.00	11.00	11.00	11.00	11.00	55.00
2.5	Subscription /books and Reading Materials	11.00	11.00	11.00	11.00	11.00	55.00
2.6	Reproduction of forms and materials	6.00	6.00	6.00	6.00	6.00	30.00
Sub Total2		89.00	89.00	89.00	89.00	89.00	445.00
3	Programme Costs						
3.1	Physio/Occpational Equipment and School Materials	33.00	33.00	33.00	33.00	33.00	165.00
3.2	Kits and toys	22.00	22.00	22.00	22.00	22.00	110.00
3.3	Local Mobilization (Parents Meeting)	33.00	33.00	33.00	33.00	33.00	165.00
Sub Total 3		88.00	88.00	88.00	88.00	88.00	440.00
4	Field Visit						
4.1	Central office	134.00	134.00	134.00	134.00	134.00	670.00
Sub Total 4		134.00	134.00	134.00	134.00	134.00	670.00
6	Workshops/seminars/training	67.00	73.00	81.00	89.00	98.00	408.00

Sub Total5		67.00	73.00	81.00	89.00	98.00	408.00
7	Monitoring and Supervision & reporting	67.00	73.00	81.00	89.00	98.00	408.00
Sub total 6		67.00	73.00	81.00	89.00	98.00	408.00
Total		1,426.00	1,633.00	1,679.00	1,725.00	1,773.00	8,236.00