

Self-help Group for Cerebral Palsy, Nepal

Annual Report

2067-68 BS (July 2010-July 2011)

Dear Friends,

The SGCP continued providing services to children and adult with cp and neurological disorders with additional interventions and understandings throughout the year 2067/68. Broadcast in Nepal Television became instrumental in exposing the services of SGCP to wider population of the country. However, referrals through parents and health institutions cannot be ignored. SGCP also noticed that more of the children visited are young, which provided opportunity for early interventions. Care centers have emerged and demand from parents were recognized.

This annual report tries to bring some activities into light with some qualitative and quantitative information. All interested persons are welcome to contact us for further information.

Thank you,

Bimal L Shrestha
CEO/SGCP

Botox Injection

SGCP administered Botox injections to eight children with the help of the National Medical College in Kathmandu. Children were identified through a series of assessments in collaboration with Prof. Gunter Gross-Selbeck and Sr. PT Claudia

Gross-Selbeck, the visiting experts from Senior Expert Service (Germany).



Dr. Ritesh is administering Botox injection in National Medical College.

At a later stage Dr. Ritesh Thapa (SGCP Resident Doctor) led the team and Dr. Uli Bettendorf (Germany) guided administration of the injections. A systematic follow-up plan was developed with the team of physiotherapists and has been conducted.

Assessment camps

Altogether 28 assessment camps were organized in 14 districts of the county to provide services to some 547 children with neurological problems in urban and rural Nepal.



PT Sarana demonstrating on the use of special chair in a camp.



Members of the Mobile Team examines a case in Sunsari district

The camps also served to raise awareness and build collaborative relationships with local expertise, hospitals and rehabilitation institutions. A team with the Resident Doctor, physiotherapist and field staff ran the camps with success.

Cases at the Centre

There was a steady flow of cases to the centre throughout the year. The flow was highest in the month of Asar (June/July) with 54 cases and lowest in the month of Mansir (November/December) with 32 cases. Nearly 600 parents with their children visited the centre for medical, therapeutic and other services including social counseling and psychological tests. At the centre alone 427 cases were medically examined. The centre also trains parents in physiotherapy routines and exercises that they can perform on their own with their children at home. This has been an important initiative in educating parents, helping them appreciate how their children can benefit from their proactive involvement in conducting regular therapy in the home environment.

Cases of children with Mental Retardation

Children with Mental Retardation (MR) are frequently referred to SGCP at the Centre and rurally, even when MR is not related to Cerebral Palsy (CP). Since demand for assistance with children with MR is high, and provision of services are low, SGCP does not deny such approaches and attempts to assist with services when possible. For example half of the cases seen at the assessment camps are MR cases not related to CP.



Senior Expert Dr. Birgit examining a child with Manoj at CPRC.

As a result of this SGCP has begun to develop some expertise in the field of MR and now also provides training to staff to deal with MR cases. A short training for the assessment of MR children was conducted for centre and field staff with the help of Dr. Birgit Fritzweiler (Germany) from the Senior Expert Service. This initiative may lead SGCP to widen their services to include children with neurological problems other than CP.



The laughing twins!! A rarest case called Angelman Syndrome (also known as happy - puppet - syndrome), found in Biratnagar medical camp.

CPRC Data Table

Service	Number of beneficiary children
Medical assessment	1074
Psychological assessment	65
Botox Injection	8
Therapeutic treatment	596
Parental Counseling (number of families serviced)	37 (families)

SEP children sent to normal school

Two children (a boy and a girl) from the SGCP Special Education Programme (SEP) were sent to normal schools in Kathmandu. These children had attended the SEP for over 2 years learning basic education and Activities of Daily Living. One of the main priorities of the SEP is to prepare children for inclusion in normal schools whenever possible. The main obstacles preventing inclusion is the lack of adapted physical facilities, therapy and special needs trained teachers in normal schools.

SEP Classes

Twelve new children were enrolled in four different groups of the SEP. Six children left the SEP for various reasons. The total number of children / young adults in the SEP at year end was 32. One new teacher was recruited and one enthusiastic volunteer teacher continued with ongoing service.

Computer Class

The Computer Class was the most popular activity of the SEP with the largest number of participants (35), including the Vocational Training Unit (VTU). The computer class is able to provide suitable instruments and learning programmes depending upon the capacity of participants, such that 19 use joysticks, 12 use a mouse and 5 children use switch. Some children are able to use a combination of instruments. Through the use of computers, lessons in English and Science topics were also introduced. Large sized keyboard from Holland were a great help for children in the computer class. Participation in the computer class also helped children with communication skills, hand-eye coordination, confidence and concentration levels.

Empowering children

SGCP has been providing Vocational Training to 10 children of ages ranging from 14 to 28 years old. The list of products prepared by the Vocational Training Unit (VTU) include: Cards, Dye Candles, Wrapping paper, Carpets, Handkerchiefs, Tea Mats, Book Marks, Herbal Salt, Patch Cross Stitch Towels, Paintings, Aprons, Pot Holders, Message Pads, Pen Holders, Christmas Cakes, Biscuits, Envelopes. Apart from production and marketing, the VTU also

conducts various visits including regular home visits, exposure visits, training etc.



The VTU Staff make home visits to every participant at least once a month. In running the VTU SGCP has collaborated with Sana Hastakala, a famous Handicraft organization and shop, in order to share expenses, staff skills and marketing responsibilities. Sana Hastakala was identified as a suitable retail outlet for the VTU products and has recently added a section where the products prepared by the children and parents of VTU are displayed and sold. This initiative stands to provide good publicity for the VTU products.

Rotary support

With the initiation of the Rotary Club of Patan Durbar Square two projects with grant support from Rotary International (RI) were successfully carried out. The first one focused on the improvement of school facilities in 78 schools in SGCP districts. The facilities provided included ramps, disabled friendly toilets, the installation of grab rails, disabled friendly classroom chairs and tables. In addition to RI, the Rotary Club of Amagasaki East (Japan) and the Rotary Club of Patan Durbar Square also contributed funds towards this project.

The second project provided the Vocational Unit with the facilities of solar

powered electricity, computers, workshop equipment and furniture. Besides RI the other funding clubs are the Rotary Clubs of Drechterland and Enkhuizend, both from Holland, and the Rotary Club of Patan Durbar Square.

A collaboration with the Rotary Club of Himalaya Patan was also established to provide special chairs and tables for over 100 children to use at home in 2012.



Children at Home

SGCP continued to provide support to children in their homes through its home visit program with 16 home visitors operating in 13 rural districts of Nepal and in the Kathmandu Valley. Networking with local organizations has been expanded with more partnerships created through the efforts of home visitors. Over 829 children were provided with required services through regular visits from of home visitors and an additional 396 children were also reached. The home visitors also identified over 202 new cases and initiated the enrolment of 42 children in normal schools during this period. Nawal Parasi was selected as a new district for home visit activity with help of donor support from an individual in Canada.

Care Centers

Three care centers are successfully operating in the Kathmandu valley servicing a total of 23 children and young adults, with a very high rate of attendance. The care centre in Budhanikantha (7 children) is well organized but requires considerable technical support. The



Gathaghar care centre in Bhaktapur (9 children) is fully run by parents. This has been a necessity and proved a valuable model for parental involvement. However technical back-up and resources are required. The care centre at Dididai Room in Bal Mandir (7 children) has already set an example in providing care for severely affected children and young girls.



Passion for Learning !!

Support to Jhamak, the writer and poet.



Writer Jhamak Ghimire, self educated writer affected by Cerebral Palsy, with the bouquet of flowers from SGCP Garden.



Newly built toilet and toilet facilities for self trained writer poet Jhamak Ghimire, with the support of Nepal Relief Association, Germany.



List of Partner Organizations

As networking with other organizations helps reach more cases, SGCP has now established formal links with the following national organizations.

Name	Address
Sewa Foundation	Tulsipur, Dang
Palpa CBR	Palpa
Partnership for New Life	Bhairahawa
Rural Rehabilitation and Upgrade Center for Oppressed and Disabled	Charikot, Dolkha
Apanga Sewa Sangh	Dhankuta
Biratnagar CBR	Morang
Sathi Sansar	Kaski
RECED	Tanahu
Nepal Children's Association	Kathmandu
KIKA Bal Bikas	Kathmandu
National Medical College	Kathmandu
Maternity Hospital	Kathmandu

Volunteers

The flow of volunteers at SGCP continued throughout the year. Some 79 volunteers, including 15 students, were involved from 7 countries, 34 being volunteers from Nepal. Projects Abroad, an international organization, provided 22 volunteers. The duration of volunteer stay in SGCP ranged from one week to one year. 22 Volunteers worked for 4 weeks and 11 Volunteers worked for 12 weeks. Most of the volunteers are professional and experienced.

Donor Agencies:

Donor Agencies	Focus Area
Saraswoti Foundation, Switzerland	Special Education, Management
Siddhartha Foundation, Germany	Child Care at Home
Lion's Club, Duesseldorf (Germany)	Medical and Psychological assessments, medicine, physiotherapy
Stichting Liliane Fonds, Holland	Special Education and Child Care at Home
Stichting 'Holland Building' Nepal	Child Care at home, infrastructure development
Stichting Maha Mata, Netherlands	Child Care at home
Nepal Relief Association, Germany	Child Care at home
Nepal CP School Charity, Ireland	Special Education, infrastructure development
Rebecca Fritz, Austria	Child Care at Home
Dididai, Spain	Care Center
A Heart for Children, Germany	Doctor and Other medical support
Bhumi Food production, Nepal	Care Center
Ministry of Women, Children and Social Welfare, Nepal	Child Care
Deepu Mirchandani, Canada	Child Care at home

In addition to the above, volunteers were provided by the following institutions; Senior Expert Service (Germany), Project Abroad, Cross Boarder (Holland), Leeds Metropolitan Hospital (UK). A number of independent volunteers also provided various services.

Moving Ahead for Designing the Future

A study was carried out to find out the situation of 177 children with neurological disorders (ND) integrated in normal schools by SGCP. On the basis of data collected from 13 SGCP districts the study team put forward following findings:

- 93 percent of girls and 85 percent of boys were continuing schooling, showing that there was very high retention among ND children.
- Parents' continued interest towards education
- ND children's schooling is a recent phenomenon and that they are late starter.
- Home related reasons to dropout included difficulty to commute to school, distance to school, problems of escorting and accompanying, inadequate help from the family, and economic problems.
- School related reasons of dropout includes teachers are unaware ND, 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;
- Child's own physical and mental situation was the main child related reasons for dropout.
- Home Visitors from the SGCP had motivated parents to enroll their child in school.
- Schooling of ND children has been a neglected reality in Nepal and even the government was doing nothing in this regard.

- Classroom and school environment was not ND child-friendly
- Parents reported many benefits of schooling or positive changes in ND children after schooling.
- Majority of continuing ND children said that they liked going school, were regular in attending the school, and liked their teachers and peers.
- Critical finding was that the sheer denial of right to education to ND children.

The SGCP Board

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