

PROJECT DETAILS

1.	Project number	24722/5/43
2.	Project title	Jyoti Kiran School for Cerebral Palsied Children
3.	Name and address of the project holder	Mr. Amitab Mehrotra Founder Chairperson & Director School for Potential Advancement and Restoration of Confidence (SPARC), India Bharat Sadan, Tilak Vihar, Sitapur Road Lucknow – 226020 Telephone no. +91- 522 2368608 Fax No. +91-522 2759942 Email: sparc_india@yahoo.com , sparcindia@rediffmail.com
4.	Legal status	<ul style="list-style-type: none"> • Registered under Registrar Firms and Societies, UP, 597, dated 9th July 1996 • Registered under Foreign Contribution Registration Act, 1976, bearing registration no. 136550120 dated 26th May 1999 • Registered under Income Tax Act, 1961 under the 12A provisions bearing registration no. U/S 12A, 58-59 (56) dated 8th July 1997
5.	Project Sanctioned Amount	Rs. 2,441,992.00
6.	Project studied by	<ul style="list-style-type: none"> ▪ Mr. Kh. Gyanen Angom Sr. Executive, Programme, Head Office ▪ Ms. Manorama Jana State Coordinator, UP
7.	Date of visit	15 th – 16 th July 2008
8.	Purpose of visit	Mid Term Review
9.	Area visited	<ul style="list-style-type: none"> • Jyoti Kiran School • Pathshala, (NFE centre) Manka Ganj, Khada, Sitapur Road • Office of the organisaiton
10.	Person contacted	<ul style="list-style-type: none"> • Mr. Amitabh Mehrotra – Director • Mrs. Mridula Mehrotra – Special Teacher • Mr. Rajeshawar Nath – Centre In-charge • Ms. Maya Roy Choudhary – Speech Therapist • Teachers and Physiotherapist of the School • Parents Support Group • Children and their parents of School and Pathshala Centre • Advocacy Group • Accountant

CHAPTER 1

INTRODUCTION

1.1 Background

SPARC, India, is a non-governmental organisation (NGO) working for Cerebral Palsied (CP) children. SPARC, India is the only NGO in UP, especially working for these children. Mr. Amitabh Mehrotra, Founder Chairperson of the organisation, himself is Cerebral Palsied. He along with likeminded people established SPARC-India in 1998.

While India's economy growth rate has risen, 35% of the population still lives below the poverty line and 39% of adults are illiterate. The number of disabled people would be around 55 million. Despite the introduction of legislation like the Persons with Disabilities Act, disabled people are amongst the most disempowered groups in India. They are constantly faced with discrimination and are subjected to neglect, prejudice, revulsion, rejection and pity. The insurmountable barriers that exist in society (economic, educational, architectural, legal, health) prevent people with disabilities from leading a fulfilling life and achieving their full potential.

In India there are two institutions, National Sample Survey Organizations and Census of India, which collect national level data on the nature and magnitude of disability in the country. However, the two insitutions have different deifinitions of disability which differs their estimated population of disabled people. There is no separate data or information available on Cerebral Palsy but often the affected people are referred to the category of Mentally Retarded (MR).

Jyoti Kiran School (JKS) is an integrated school for Cerebral Palsied Children, established in January 2003. After years of service, the organisation felt the need to change their approach from Charity to Rights Based with equal participation of persons living with Cerebral Palsy and parents to ensure the rights of disability. The organisation has been working in urban slums of Lucknow City and rural communities of Barabanki district of Uttar Pradesh (UP) state.

1.2 Context of the study

SPARC, India has been implementing a project named Jyoti Kiran School (JKS) for Cerebral Palsied. The aim of the project is to identify cerebral palsied children, enroll them in JKS for basic education, provide therapeutic treatment, mainstreaming them to formal education, provide basic vocational skills for children above 14 years and networking and advocacy for the rights of disability.

Different definitions of disability are introduced for various purposes and, as such, they have been based on various criteria. No single universal standard exists in the world in order to evaluate disability. In common parlance, different terms such as disabled, handicapped, crippled, physically challenged are used.

The project is a continuation of past project and is being implemented from January 2008. In order to review the progress of first six month of the project, a mid-term review was conducted. IGSSS conducted the study for two days from 15th to 16th July 2008. Mr. Kh. Gyanen, Sr. Programme Executive, HO and Ms. Manorama Jana, State Coordinator, UP, formed the two member team of the study.

1.3 Objectives of the study

The objectives of the study were to assess the progress of the project of last six months, timeliness with determined budgets, community outreach of intervention, efforts to scale up the project, and management of funds. It was also to assess the specific questions mentioned by SKN.

1.4 Methodology of the study

Firstly the study team gathered all the required documents from the organisation. The documents were studied thoroughly and key points were highlighted for assessment. Assessment was made through interacting with children and their parents, project staff, reviewing of records, funds flow and programme management system.

The study team also visited the Pathshala centre running at Khedra Slum area.

CHAPTER

2.1 PLAN ACTIVITIES AND FINDINGS

Review has been made on proposed activities and findings are as follows:

2.1.1 Out Patient Department (OPD) Services

The OPD service is an ongoing activity and managed by two professional - Occupational Therapist and Speech Therapist. It was operated in the premises of Jyoti Kiran School from 10.00 a.m. to 4.00 p.m.

The centre is providing free health check up to Cerebral Palsied children. The Therapists examine the children and recommend appropriate therapeutic treatment as per the need. Counseling is also provided to parents to make them understand the problems and needs of the child. They informed that parental support is very important for these children but most of the parents are not supportive due to lack of awareness, indifferent attitude and poverty.

The study team felt that to manage these children lot of patience and determination is required. The team observed that the OPD professional are dedicated and affectionate to the children.

Counselor is part of the proposed professional team of OPD service. But it was found that the Counselor is not yet appointed. They informed that the post was advertised in the local newspaper but they did not find a suitable or qualified person. The study team shared a concern that the delay in appointing of required staff would affect the project, as Counselor is one of the important personnel of OPD services. It was suggested to appoint the required staff as soon as possible.

2.1.2 Academic programme

Academic programme/Jyoti Kiran School is a main activity of the project. The academic year of the programme is from January to December. Currently there are 37 children out of which 22 are boys and 15 are girls. It has six different types of classes Home Management Non-Educable Group, Home Management Educable Group, Transition Class, Class I, Class II and Class III. The subjects taught at the school are English, Hindi, Social Science and Mathematics. For Class I to III, the same syllabus is followed as prescribed by the State Education Board. The timing of the school is from 10.00 a.m. to 4.00 p.m.

Children are enrolled in different classes as per their capacity. For each individual child, case study is prepared and curriculum is designed. A format is also developed to assess the progress of the child. For each child weekly, monthly and quarterly goal and indicators are set. Physiotherapists, Speech Therapist and Occupational Therapists give their input to the children.

A non-formal education centre named Pathshala, is being run for poor and Physically Challenged children at Khedra slum community. In that centre 34 children were enrolled out of which 10 are physically challenged children – 1 Cerebral Palsy, 3 Deaf, 2 affected by

Polio, 1 Blind, 2 Mentally Retarded, and 1 Dumb. Children were provided with books and copies. Records are maintained and kept at the centre. The timing of the centre is from 10.00 a.m. to 1.00 p.m.

The organisation informed that many people have visited the organisation seeking for the admission of their children. But due to paucity of resources and space JKS cannot accommodate more children. The organisation has made efforts to expand their programmes by visiting various Ministries of State and Central Government. The organisation has approached Lucknow Development Authority, Government of UP, for the donation of land but they did not receive a positive response from the Government. They also informed that if the Government provide land to them then they will approach Corporate or Individual for donation to construction building.

The programme is implemented as per the academic year followed in the school. It was observed the academic programme is going on well and parents send their children regularly. Transportation facility is also provided to the children with nominal fee of Rs. 500 per month for fuel charges.

The project staff particularly Teachers and Physiotherapists are qualified and have special training for handling these children.

It was found that the organisation is yet to appoint the Project Coordinator and Special Cerebral Palsied Teacher. Their reason given by them was that they were not able to find suitable persons for the post. The study team shared that for the effective implementation of the project, the required staff should be appointed at the earliest.

List of children is attached as Annexure 1.

2.1.3 Counseling Services

Counseling is provided to parents for psychological and moral support as many parents have lost hopes for their children. In order to sensitise and aware them the problems faced by their children regular counseling is provided at the school. Parents are invited in school on regular interval to discuss the progress of their children. They are also invited to discussions with Experts on basic home management skills for handling Cerebral Palsied children.

Home visit and special counseling session once in two month are also conducted for those parents who need attention. It was observed that the counseling is of informal in nature and conducted as and when the parents visit the school. Home visit or special counseling session report are being maintained but they do not maintain records for regular counseling conducted at the school. It was suggested that certain steps should be followed for the counseling and maintenance of the records for future reference.

It was found that counseling helps the parents to understand the problems of their children. The team felt that for certain parent, expert's help is essential for attitudinal change. Counseling was provided by School Teachers and physiotherapists. But the team felt that it is not as effective as counselling by trained Counselor. The study team suggested to appoint the Counselor immediately.

2.1.4 Therapeutic Intervention

The problems of Cerebral Palsied can be reduced with regular therapeutic intervention like Physiotherapy, Speech Therapy, Home Management and Occupational Therapy. It was found that therapeutic interventions are regularly provided to children. They informed that therapeutic intervention is not uniform for all the children as each child has different needs. For each child intervention plan is prepared. It was observed that therapeutic intervention is slow process but it improves the coping mechanism of Cerebral Palsied children in the long run. Many parents shared that they observed the improvement of the child. They expressed their satisfaction and gratitude towards the organisation and SKN for the support. The organisation has appointed three Physiotherapists for this programme.

2.1.5 Formation of Parents Support Group (PSG)

The organisation has formed one Parents Support Group. The group members are parents of Cerebral Palsied children of Jyoti Kiran School. The group was formed to provide a platform to the parents to discuss about the problems of their Cerebral Palsied children and find ways with collective action. The group meets every second Saturday for two hours.

The study team had a meeting with the group. More than 20 parents were present for the meeting. Most of the parents shared that SPARC, India, is the only institution in the city providing the multipurpose facilities for Cerebral Palsied children under one roof. They said that without the support of the organisation their children would have been isolated at home without any hope.

The study team observed that though the group conducted regular meeting it merely act as support system to scale up for the intervention of rights of disabled people. Apart from the regular agenda they did not discuss developmental issues of Cerebral Palsied children. It was found that the group was not involved in the activities of Advocacy Group.

The study team suggested that there is a need to scale up the intervention from need based to rights based, which is planned in the project. It was also suggested that group needs to be strengthened and network with various organizations or forums or stakeholders for advocacy initiative towards rights of Cerebral Palsied children.

It was suggested that for equal participation and ownership, the group should form a committee of few members who can coordinate the group and plan for future action. Action oriented activity can be initiated by identifying Government schemes and programmes of disability, resource mapping exercises, budget allocation of disability, identify NGOs working on disability, sharing of information and dissemination related to disability etc. This information can be collected from various sources, which are easily available in Government Department, NGOs or institutions. If needed proper legal action can be taken by using RTI and PIL in democratic approach.

2.1.6 Formation of Advocacy Group

The organisation has formed one Advocacy Group in which all the members are disabled and they are from different walks of society. The name of this group is “Nai Rahein”, which means “New Hopes”. The group has 25 members and few of them are educated and some are illiterate. The group has a structure and roles are assigned. The group has been formed to initiate a sustained advocacy campaign to achieve accessibility, justice, and mainstream disability within development.

The group has initiated a Social Audit on the accessibility of Government Departments by disabled people. Some of the members who involved in the Audit informed that most of the Government departments located in the city and not accessible by disabled people. They said that after the study is completed they would initiate an advocacy campaign for the accessibility rights of the disabled people. The group also plans to take up action on inclusion rights of disability by sensitizing the parents and community. It was found that the group members are vocal, lively and enthusiastic. Bal Anand, Secretary of the Group, is an educated person and has completed his graduation. He has an aim to form a Hockey Club for disabled people. Some of the group members also engaged in income generation activities like selling of vegetables and electricity work. The group has also started training in vocational skills like sweet box making which is relatively easier.

The study team observed that the group members are young and energetic. It was suggested that the group could be strengthened by providing capacity building workshop on advocacy, community awareness, how to access to government schemes and programmes of disability etc. The study team suggested the Parents Support Group should also be part of Advocacy Group to strengthen the group for collective action.

2.2 ASPECTS RAISED BY SKN

2.2.1 Efficiently of the project and feasibility to increase the number of children involved

The project is implementing quite well in terms of enrollment of children in the Academic Programme. The academic programme was started with two children in 2003 now it has 35 children. Jyoti Kiran School has also upgraded the classes from Class II to Class III. Currently the intervention of the project is observed to be more service oriented. Though groups have been formed they need to be strengthened in a participatory approach towards the rights of disabled people. The groups are functioning independently and required to synchronize and strengthen for the collective action. It was suggested that more input is required for attitudinal change of parents towards addressing the rights of their children. The study team observed that there is a feasibility to increase the number of children, if proper strategy is adopted.

2.2.2 Possibilities to mainstream children into formal education

Mainstreaming of children is one of the strategies of the project. In the past year, the organisation has mainstreamed five children into formal education out of which four are boys and one is girl. The organisation conducted follow-up through contacts with parents but not regularly.

In this project activity like awareness and sensitization programmes of schools will help the organisation to establish contact with schools for integration of these children. However, the parental support and cooperation from schools are equally important for integration of children into formal education. The organisation has to establish effective partnership with NGOs, stakeholders, schools, and Government department so that these children can be mainstreamed.

2.2.3 Possibilities for linkage with networks and NGOs

Mr. Amitabh, is a member of various forums at state and regional levels. He lobbies with State and Central Government for greater awareness on inclusion and the rights of disability. He approached to Lucknow Development Authority for the donation of land. He contacted with the Ministry of Social Justice and Empowerment for the support of the cause. Though he has taken many initiatives there is a lack of involvement of project staff. It was observed that the project staff have less involvement in planning and decision making. The study team felt that their linkage efforts could be strengthened if he promote the leadership amongst the project staff and assign responsibilities.

2.2.4 Lobby towards the Government

The organisation has taken efforts to get support of the Government. They have lobbied with State and Central Government for greater awareness on inclusion and rights of disabled people. The organisation has approached Lucknow Development Authority for the donation of land. They have also contacted with Ministry of Social Justice and Empowerment for the support of the cause. The State Bank of India has donated a bus to the organisation.

The study team suggested that their efforts could be scaled up through resource mapping exercises, dissemination of information through press release, media advocacy, interface programme with Government Department and School authority, lobby with State Transport Authority for free transport or utility for disabled people. It was also suggested that parents and groups should also participate in the campaign.

2.2.5 Formulating goals and indicators

The past two year's intervention was to identify the Cerebral Palsied children, enroll them in JKS and mainstream them into formal education. So far five children have been enrolled in formal education. Every year the school is adding up new classes and some children have been upgraded to next standard. The Academic Programme is observed to be doing well and children are attending the classes regularly. In the third year, the project will attempt to intervene more into community sensitization, formation of pressure groups and lobby and advocacy with schools and government departments. Though the project is to ensure rights

of disabled people, it was decided to formulate short term goals and indicators to be achieved within the project period. With the inputs of study team the organisation has developed a Logical Framework Analysis (LFA) of the project with timeline. Please find attached LFA for reference in Annexure 2.

2.3 Capacity of the staff

Mr. Amitabh, Executive Director, is a Cerebral Palsied person and knows the problems and issues surrounding Cerebral Palsied children. He shares the issue at the appropriate platforms and forums. He shares his personnel experience and knowledge to his staff. The project staff are qualified and have the capacity to handle these children. Most of the staff particularly the teachers are female and two of them are physically challenged. The staff have the experience to work with these children and good in administration of in-house activities but they need to improve their capacity in terms of lobbying and networking, planning strategically to raise the issue of disabled people and accessing policies and programmes. Please find attached list of staff as Annexure 3.

2.4 Monitoring and Reporting System

The organisation has set a monitoring system by assigning job responsibilities to all the project staff. A monitoring format is developed to check the progress of the child and discuss with the parents regularly. For each child a case study is prepared and treatment plan is made by the teachers and physiotherapist. Beneficiary assessment is undertaken through regular dialogues with the parents in order to solicit feedback for improvement.

The field-based activity is implemented with the instruction of the Chief Functionary. Activities reports were prepared and maintained. The Project Report is prepared by the Chief Functionary with the help of project staff.

The staff meetings are conducted every month to discuss about the project. Though each staff prepared action plan for each child but there is lack of planning for field-based activities. It was found that the organisation has prepared action plan only for the Academic Programme and not for field based activities. It was suggested that the plan of action should be prepared for overall of the project so as to implement the activity on time and achieve the desired results. With the inputs of study team the organisation has developed the plan of action and attached as Annexure 2.

2.5 Funds Flow System

The organisation has no written policy but they do practice certain systems and procedures for funds flow. The overall project funds are managed by the Executive Director. The Accountant manage the day-to-day accounting and maintenance of records. All the accounts are maintained in Tally. It was found that payments above Rs. 2000/- were paid through cheques. The staff salaries also paid through cheques and signatures were obtained.

The Chief Accountant releases the payment as per the requisite submitted by the staff subject to verification of Executive Director. The Cheque signatories are Executive Director

and Treasurer. The financial expenditure statement is updated every quarter to the Board. In that Programme matters are also discussed. Annual audit is conducted and FC-3 return is being filed.

The study team found that that the present project started from April 2008 though in the contract letter the project duration is mentioned as January to December 2008. It was also found that the past project has been extended upto March 2008 though the project was supposed to be completed by December 2007. It was informed that the permission has been taken from SKN to utilize the balance amount upto March 2008. Few observations have been made for funds utilization as follows-

- By the end of December 2007, the balance amount of past project was Rs. 389440.50/-(23.41 %).
- In the past project apart from Academic programme, most of the community-based activities were implemented during the extension period of the project, which shows lack of planning. It was informed that advocacy meetings were not conducted due to unavailability of resource persons.
- Uptil December 2007, not a single amount was spent for the budget heads like Accountant salary, advocacy meeting, and contacting local doctors and professionals. It was informed that the Accountant salary was paid from Actionaid Project till December 2007 and from January 2008 to March 2008, the salary was paid from SKN project. The salary was part payment and it should have been released on monthly basis, which is not a sign of good financial system.
- It was found that during the extension period (Jan. to Mar. 08), the total expenditure amount including local contribution was Rs. 419744/-, out of which Rs. 30155/- was spent on Programme activities, which is 7.1%. The major amount was utilized for staff salary and vehicle maintenance costs.
- Certain bills and vouchers were found missing. In some vouchers the counter signature of the Accountant was found to be missing. It was suggested to maintain and update account on daily basis.

Chapter 3

OBSERVATIONS AND RECOMMENDATIONS

3.1 The observations and recommendations are as follows:

- i. The last project was sanctioned for 9 months from April to December 2007; however, it was extended upto March 2008 so as to utilize the balance amount.
- ii. In the last project major activities have been implemented during the extension period of the project.
- iii. The current project has been sanctioned for 12 months from January 2008 to December 2008 however it could only start from April 2008. The first installment of the project was received in April 2008.
- iv. Apart from Academic Programme, no action plan is developed for the implementation of field-based activities. It was suggested that plan of action should be prepared with proper timeline so as to achieve the desired results.
- v. The existing project staff have requisite qualification and are capable to handle the Cerebral Palsied children. However, important key staff like Project Coordinator, Social Worker Counsellor and Special Cerebral Palsied teacher are yet to be appointed. It was suggested to appoint the required staff as soon as possible and inform SKN.
- vi. Mr. Amitabh, Executive Director is the only staff who has programmatic skills for planning and implementation of the project. In his absence the organisation has no other capable staff who can manage the project. It was suggested that the key staff, Project Coordinator, should be appointed at the earliest for better coordination, planning and execution of the project.
- vii. The Advocacy Group is vocal about the issue of disability. This group also conducted Social Audit of various Government Building for accessibility of disability. They have planned to file a PIL to concerned authority on the rights accessibility of disabled people.
- viii. It was also observed that the approach of Advocacy Group is more on income generation activity. The team shared a view that the livelihood is important issue for most deprived group however it would be possible only through lobby and advocacy with the concerned authority to access the facilities provided by the Government. To do that certain action oriented activities could be implemented by identify the government schemes and programmes for disabled people, resource mapping and budgetary allocation exercise, raise the issue of disability through media advocacy, networking with likeminded NGOs, consultation on rights of disabled people, interface programmes for the accountability of concerned authority etc.
- ix. It was found that the Parents Support Group is not involved in Advocacy Group. It was suggested that PSG should be involved to strengthen the group and for collective action.
- x. It was suggested that the workshop could be conducted for Advocacy Group and Parents Support Group on legal and social aspects like RTI, PIL, Welfare Schemes and networking and advocacy.
- xi. The Accounting system needs to be improved and proper training should be provided to Accountant.

- xii. The organisation has planned to extend the project upto March 2009. It was suggested that written permission should be taken from SKN for the extension if any.

The project started in April 2008. The project action plan has been formulated after field visit. The Academic Programme is going on well as per the plan. The field based activity has been planned from July 2008. The first instalment was received in April 2008 and upto June 2008, only 40% (Rs. 416539/- by 30th June 2008) of funds has been utilised. After analysing the activity plan and funds utilisation, IGSSS recommend to release second instalment by the end of August 2008.