

Working with Carers for Carers

Addressing the needs of the carers of children with cerebral palsy, mental retardation, autism and multiple disabilities

Background to the project - The life of a carer

Caring can be a rewarding experience, but it can also have a significant negative impact on carers as they focus on the needs of the person they are caring for, leaving little time to take care of their own needs.

Children with cerebral palsy, mental retardation, multiple disabilities and autism have complex health, developmental and social needs and their care is usually carried out by one main carer, most commonly the mother.



Disabled children and their carers in Kurnool District

Carers are hard hit in a number of different ways as a result of their caring role. These include:

- loss of employment
- reduction in earnings
- loss of education (in the case of children and young people)
- poor health
- reduction in social contacts
- reduction in opportunities to participate in family and socio-cultural activities.

"We are voiceless, the most marginalised and excluded in socio-cultural activities"
Ruby Singh, mother to a child with autism

Over time, the physical, mental and emotional health of the carer becomes affected, which means that they are less able to care for their child effectively. The health and wellbeing of the child is then compromised.

Aim of the project

The aim of the project is to enable the **82 carers of children with cerebral palsy, mental retardation, multiple disabilities and autism** in Kurnool district, Andhra Pradesh to

- recognise the contribution they are making to the child they are caring for and to the wider society,
- meet together for emotional support and
- enhance their quality of life through the provision of counselling and medical services.

Project Objectives and Activities:

The Project's activities will be conducted by SACRED staff and co-ordinated by a designated Project Co-ordinator, with input from Carers Worldwide for project development, training, review and monitoring.

Objective 1 – To assess the individual needs of the 82 carers and devise ways of addressing these

Activities to meet this objective:

- Design and develop a format for developing individual carer profiles.
- Conduct training on how to assess the individual needs of the carers and devise a means to address these through an appropriate use of the different activities as detailed below.

Objective 2 – To build the capacity of the SACRED staff to initiate and develop support for carers

Activities to meet this objective:

- Conduct training sessions for senior staff and disability workers focussing on:
 - broadening their understanding of the needs of carers;
 - developing communication skills;
 - listening and basic counselling skills;
 - developing their knowledge of the activities to be undertaken in the project.
- Conduct training on creating carers' profiles and undertaking ongoing data collection.
- Work jointly with staff to develop documentation relating to the project and recording the learning generated, including life stories.
- Conduct end of project review with the staff in order to assess its progress and impact.

Objective 3 – To assist carers to develop a greater knowledge and understanding of their role as carers, to recognise their rights, to support each other emotionally and to advocate for themselves, both as individuals and as a group

Activities to meet this objective:

- Form carers groups which will meet monthly, facilitated by SACRED staff.
- Conduct short stay camps for carers, which will provide respite from their caring responsibilities and also be an opportunity for them to meet other carers and share their experiences.
- Provide more in-depth information to carers about the condition of the person for whom they are caring and ways in which they can improve their support for them.
- Provide support and practical assistance to build up the skills of the carers to meet their own needs, for example the importance of looking after themselves.
- Encourage carers to develop their own coping strategies and to recognise their own needs as well as those of the person for whom they are caring.
- Train carers to deal with conflict in the family and ensure that they have access to support structures outside the immediate family.
- Actively encourage carers to share their own experiences and issues within the carers group. Not only will this enable the carers to gain support but it will also help the group to develop a forum for learning and mutual benefit.

Objective 4 – To provide counselling and medical support for carers to ensure their emotional and physical wellbeing

Activities to meet this objective:

- Identify suitably qualified professional counsellor in the local area
- Refer carers requiring counselling support to meetings with the counsellor, which can continue on an ongoing basis as required
- Regular meetings between the counsellor and the SACRED pilot project co-ordinator to ensure follow up between counselling sessions
- Refer carers requiring medical support to the appropriate professionals

Monitoring

Carers Worldwide and SACRED will carefully monitor and evaluate the programme throughout its course. SACRED staff members will ensure that all carers meetings and training workshops are rigorously documented and subsequently analysed. In addition, we will write up individual life stories to record carers' voices.

We will conduct formal reviews after six months and at the end of the project. We will prepare an end of project report for distribution within the Carers Worldwide network and to funders.

Outcomes

Expected outcomes include:

- Individual profiles developed for the 82 carers and baseline data collected
- 2 training sessions held with project staff
- 12 life stories researched and written up
- 10 carers groups formed
- Monthly meetings held with each group
- 1 short stay camp conducted for carers
- Counsellor services available monthly and carers requiring this service accessing it regularly
- Medical support provided for those carers requiring it
- End of project review conducted and report written

On-going impact of the project

Carers Worldwide's collaborative approach, along with our focus on establishing carers groups ensures that the benefits of the project will be highly sustainable. Expected impact includes:

- Increased recognition of the contribution made by carers
- Reduction in the isolation and loneliness experienced by carers
- Improved mental and physical health of carers
- Improvement in the levels of care given to children with cerebral palsy, mental retardation, multiple disabilities and autism

Carers will gain access to emotional support, medical support and greater social integration. Those involved in the project support groups will be empowered to expect and demand their rights and by working in collaboration with SACRED they will ensure that their voices are heard.

Summary budget for “Working with Carers for Carers” project

Description	Amount (in Rupees)	Notes
Staff cost	96,000	Project Co-ordinator cost
Field travel	18,000	Staff travel to carers’ homes, carers meetings, etc.
Capacity building / staff training	15,000	Training of SACRED staff - cost of training material, food and accommodation, and stationery
Promoting carers groups	20,000	Training in coping strategies, patient care and formation and running of support groups for carers.
Short stay camp for carers	15,000	Outing for carers and provision of alternative care for their disabled children
Data collection	5,000	Baseline survey – collection and collation of data, life stories. Cost of venue, stationary, contribution to participants travel to attend meetings.
Counselling and medical services	30,000	Monthly access to professional counsellor and to medical professionals as and when needed
Administration and management	6,000	Contribution to SACRED office costs and premises costs to cover extra electricity supply, telephone, stationary, etc.
Project management, monitoring and reviews	10,000	Monitoring, evaluation and documentation costs including external consultant costs
TOTAL	2,15,000	

Registration Number with National Trust: SACRED registered with Welfare of Disabled & Senior citizens of Government of Andhra Pradesh. 933/2004 of register of societies, Anantapur District is registered as per the sections 52 of Persons with Disabilities (Equal opportunities, Protection of Rights and Full participation) Act 1995. The same certificate of Registration attached for your kind information.

Society Registration Number: Regd. Soc.No 344/ 1994

Proposal submitted by:

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