

PROJECT COVER SHEET

Project title : Daya Gramam for Terminally Ill People
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Name of the organization : Daya Charitable Trust [Reg.No-737/06]
Target groups of the organization : People with Disabling Chronic Illness and Families
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I. Project summary

'*Daya Gramam*' is proposed as an alternate institutional care facility that provides institutionalized health, nursing, psychosocial and rehabilitation services along with shelter, food and clothing to terminally and chronically disabled, bedridden, destitute persons in Kerala. Aligned with our organizational vision, *Daya Gramam* aims to empower socially, physically, and mentally challenged persons to lead a near to decent and dignified life as humane persons, hand in hand with the privileged sections of the society. *Daya Gramam* will be established in 50 acres of land with a modern disabled friendly structure with all necessary amenities. These amenities include provisions for homecare, medical and nursing care alongside with psychosocial and rehabilitative services for a minimum of 1000 bedridden children and their primary caregivers. This project is proposed for a period of three calendar years for assistance. Fourth year onwards, the institution will be self sustained by using the interest rate of the seed funding secured. First year will be for land purchase and building construction. This will be followed by operational phase when prospective inmates will be recruited and begin to function. Final phase will be the period for regularizing services, staffing, selection and maintenance of the inmates through rules and regulation and standardizing services provided.

The '*Daya Gramam*' will be operational during second year of the project initiation. Most deserving persons from the pool of 1000 identified cases alongside with their primary caregivers/mothers, by *Daya Charitable Trust*, will be selected as inmates. Fourth year onwards, the '*Daya Gramam*' will be self sustaining institution catering services to terminally and chronically ill persons.

II. Organizational history, mission, vision and structure

At a tender age of 13, Sanjumon had to discontinue studies, owing to family responsibilities. His father was paralyzed and bedridden. Having no home for their own, Sanjumon had to become the sole breadwinner of his family and take care of sibling's education. Making a life staying in railway platforms, cleaning dishes, Sanjumon was first exposed to the suffering of socially neglected, disowned, mentally and physically challenged people. Having seen their suffering from close quarters, Sanjumon decided to contribute his meager income for their wellbeing.

Inspired by Mother Teresa's service and life messages, Sanjumon decided to dedicate his life

for the stigmatized, ostracized and socially excluded in the society. As a result of his organized efforts to address this noble cause; *Daya Charitable Trust* was formed in the year 2006 with following vision, mission and goals.

VISION: To empower socially, physically and mentally neglected and challenged to lead a near to normal life, hand in hand with the privileged sections of the society.

MISSION: To provide a humane living environment for the socially, physically and mentally neglected and challenged sections of the society

OUR VALUES: Love, Compassion and Trust

OUR GOALS:

- 1) To provide a humane living environment and empower the ostracized, marginalized, and abandoned sections of the society.
- 2) To provide a humane living environment and empower disowned children and women who are infected with HIV/AIDS.
- 3) To provide humane living environment and empower physically and mentally challenged sections of the society.

Concise overview of our work: We provide health, groceries, educational, and financial assistance to 300 HIV infected families and their children in Kerala. We provide this support with the help of corporate sector. We have identified nearly 1000 children in Palakkad district who are chronically disabled and bedridden due to different illness such as cerebral palsy, severe mental retardation, Down syndrome, and so on. At present, we have selected such 100 children in Palakkad district and provide Rs. 1000 for their immediate expense on monthly basis. For this scheme, we network with employees at government and private sectors.

III. Background and analysis of the problem to be addressed

Most countries are experiencing health transitions with rapidly rising burden of chronic and incurable disease. In India, chronic diseases account for 53 per cent of all deaths and 44 per cent of disability-adjusted life-years lost in the year 2005. Long-term care for such patients is emerging as the major health care issue in India. With a crude death rate of 8.28/1000 and a population of more than a billion, the total number of patients in need of palliative care services in India can, using WHO norms, be estimated at 60 per cent of all deaths, or 5.4 million people a year. Evidence suggests that the chronic disease burden is greater among the

poor who are more vulnerable for several reasons, including material deprivation and psychosocial stress, higher levels of risk behaviour, unhealthy living conditions causing increased exposure to risks and limited access to good-quality health care.

In addition, chronic diseases or conditions inflict enormous direct and indirect economic burden on the poor and push many people and their families into poverty. This complex nature of physical and psycho-social problems faced by these patients and their families demand quality medical and nursing attentions. However, the services available to people living with chronic and incurable diseases are generally inadequate and inappropriate. The present health systems with its hospital-centered services, is geared to look after patients with acute illness. Patients with chronic and incurable illness or conditions, on the other hand, need a regular system of support available in the community. In the absence of such a comprehensive system of care, many patients and their families experience poor quality of life and even early death.

Kerala is faced with second generation problems to ensure quality of life. Though the state provides reasonable access to health care facilities at village levels, rehabilitation of people living with chronically disabling terminal illness such as severe mental retardation, cerebral palsy, HIV and so on are limited. Present health care system in the district is designed primarily to meet the curative and preventive health care needs as elsewhere in Kerala. It ignores the rehabilitation needs of terminally and chronically ill persons and their families. As a result, there is a significant shortage of specialized rehabilitation facilities and helping professionals. Existing health care systems critically lack the expertise and potentials to meet the needs of chronically and terminally ill persons.

In this background, there was a recent boom in community based palliative care movement in Kerala. It is based on the principle that local communities can be empowered to identify the chronically ill (e.g., paralyzed and bedridden) and terminally ill, regardless of disease and causes of such diseases; and to support them with self sustaining community led services despite limited economic resources and outside support (Stjernsward, 2005).

This concept is appealing, and the movement has gained momentum in northern Kerala. But it does not erode the scope and need for hospice care for the terminally and chronically ill persons as envisioned in '*Daya Gramam*'. As per our field work experience, the community

based rehabilitation facilities are at the initial stage with severe deficiencies to meet the needs and overall care and support needs consistently. Further, there is a huge mismatch between the actual caregiving, support needs and community based services provided (Field note, 2014). Furthermore, urban centered hospitals, and accessibility to such hospitals, financial expenditure involved in are factors that impede availing available health care services with rehabilitation potentials. The proposed project provides long term institutionalized care services to chronically and terminally ill persons. Our argument will be strengthened with a case example.

Box-1: A Case Example

Remani (name used with permission) is a 44 years old widow, who belongs to lower socio-economic status (BPL household) with three children. This family is living within 10 km distance from district headquarter of Palakkad district. Her husband was an alcoholic and committed suicide while he was 36 years old. Her two sons Mr. Ramesh 29 yrs and Sujish, 22 years are with cerebral palsy and bedridden since birth. Their sister Ms. --- is a 19 year old girl who discontinued her elementary education and currently working in a grocery shop in order to support the household. Mother is engaged in round the clock caregiving to her two bedridden sons. Their limited income, worries on care for sons after daughter's marriage are the critical concerns of the mother with significant stress, concerns and worry about the future care. She experience substantial amount of caregiving burden, psychological distress, and she looks for alternate care facilities for her sons in long term.

Beneficiary groups: Destitute and disowned children who are bedridden and dependent due to various illnesses such as severe mental retardation, Down syndrome, cerebral palsy, cancer, and HIV and their families form the target group for 'Daya Gramam'. Such children and their families need quality and nutrition rich food, safe residential facility, and standard care, including medical and nursing care. In the absence of these, we have found many such children and their care and support needs are either neglected or inadequately addressed. It has significant implications on the quality of life and wellbeing of these children and their family members. Hence, developing systematic and institutionalized facilities envisioned in 'Daya Gramam' will help to ensure decent living for such terminally and chronically ill persons and their caregivers, thereby ensure dignity and worth of human life. We have identified 1000 chronically and terminally ill children, whose families are predominantly lower in socio-economic statuses; and whose mothers are often deserted. This has lead to inadequate care including nursing and medical care. To the best of our knowledge, there is no comprehensive rehabilitation system available in Palakkad district to cater the needs of

chronically disabled individuals or their families. In the absence of such institutionalized rehabilitation system exclusively for bedridden persons, the proposed project aims to address this noble cause by establishing a long term free residential rehabilitation care facility for bedridden individuals in Palakkad district of Kerala.

Goal of the proposed project: The proposed residential facility will be established in 50 acre of land with a modern disabled friendly structure with all necessary amenities for ‘*Daya Gramam*’. These amenities include provisions for homecare, medical and nursing care alongside with psychosocial and rehabilitative services for a minimum of 1000 bedridden children and their primary caregivers.

Objectives of the proposed project:

- 1) To purchase 50 acre of land in rural area and construct a disabled friendly structure/home to provide long term institutional care to bedridden persons and their primary caregivers.
- 2) To provide care and support related services such as primary or home care, medical and nursing care alongside with psychosocial and rehabilitative services to the chronically bedridden persons and their families.
- 3) To alleviate persons’ distress and caregiver burden through the provision of comprehensive psychosocial rehabilitation

Target group: Bedridden and completely dependent persons who need round the clock care for everyday life, irrespective of illness and their causes. We give priority to bedridden persons completely dependent on primary caregivers for everyday life. This project is proposed for a period of three calendar years for assistance. Fourth year onwards, the institution will be self sustained by using the interest rate of the seed funding secured. First year will be for land purchase and building construction. This will be followed by operational phase when prospective inmates will be recruited and begin the functioning. Final phase will be the period for systematizing services, staffing, selection and maintenance of the inmates through rules and regulation and standardizing services provided. Each phase is detailed in the following phase.

Purchase and construction phase-1: Once financial support is secured, the project shall purchase 50 acres of land. Purchase of land is with three purposes. First, a portion of the land will be used for constructing 1000 bedded disable friendly building and associated amenities.

Second, the remaining major share of the land will be used for cultivating food material including fruits, vegetables and so on for the domestic purposes. Finally, remaining land will also be used for future extension of the project.

Operational phase-2: Once the building with required amenities for ‘*Daya Gramam*’ is constructed, we will develop a staff pattern which includes physicians, nurses, pharmacist, social workers and support staff. First, a director of ‘*Daya Gramam*’ will be appointed who will be responsible for overall administration, home management and resource mobilization. He/she will also strategize the further plans for the ‘*Daya Gramam*’. His primary responsibility will be to ensure the smooth functioning of the care home. Second, one physician will be employed with expertise in working with chronic bedridden persons. Third, we will recruit a minimum of 4 nurses who are experts in this area. They will train and assist primary caregivers of the patients to provide decent, gentle and quality everyday care and support to the patients/bedridden persons. Fourth, one social worker with experience in rehabilitation will be recruited to provide psychosocial care and support as well as to facilitate rehabilitation. Further, one pharmacist will be appointed to regulate medicine at ‘*Daya Gramam.*’ Finally, support staff includes 28 staffs for multi-purpose such as cooking, cleaning, laundry, security, and housekeeping.

Table-1 details the staff and their responsibilities.

S. No	Personnel	No	Responsibility
1	Administrator/Director	05	Administration and management
2	Medical doctors	04	Primary medical care
3	Nurses	20	Primary Nursing care
4	Social workers	02	Counseling and Rehabilitation
5	Support staff	88	Cooking, cleaning, laundry, security, & house keeping Etc

Functioning phase-3: The director of the home along with the management will strategize the sustainability of the project including developing strategies for resource mobilization. Personnel plan will be developed by specifying qualification, experience, recruitment, and induction training, ongoing professional development programme and personnel management system within the organization. Roles and responsibilities will be specified to each category of staff.

Expected outcomes: During the first phase, about 50 acres of land will be purchased in the name of the proposed *Daya Gramam*. The registration of the ‘*Daya Gramam*’, detailed

planning and estimation of the ‘*Daya Gramam*’ and tenders for construction and selection of builders would be done. Further, construction of disable friendly building will be completed during the initial year. Second year onwards, the ‘*Daya Gramam*’ will be operational. Most deserving persons from the pool of 1000 identified cases along with their primary caregivers/mothers, by Daya Charitable Trust, will be selected as inmates. Simultaneously, staff recruitment, induction training, developing code of conduct and standards of care will be developed. The ‘*Daya Gramam*’ will therefore be fully operational during the second year onwards. Third year will be focused more on standardizing care and support services, staffing and their training.

Gantt chart

S. No	Mile stones to be achieved	Year-1				Year-2				Year-3			
		1	2	3	4	1	2	3	4	1	2	3	4
	Trimesters												
1	Land purchase	X											
2	Building: plan and estimate	X											
3	Tender	X											
4	Construction	X	X	X	X								
5	Recruitment of staff					X							
6	Induction training					X							
7	Recruitment of inmates						X	X	X	X	X	X	X
8	Introduction of agriculture					X	X	X	X	X	X	X	X
9	Staff development programme					X			X	X	X	X	X
10	Systematizing services									X	X	X	X

VI Project Budget

Project budget outline	Items	Indian Rupee	Phases
Land purchase – Rs.20,000/- * 5000 cents=10 crore Construction of Daya Gramam-3 lakh sqft * Rs.4000 = 120 crore (Please see the detailed breakup for construction attached)		100,000,000 1,200,000,000	Phase-1
Project Personnel * (second year)			Phase-2
Doctor salary - 4 nos-		1,920,000	Operational phase-2
Nurses Salary -20 nos-		3,600,000	
Pharmacist Salary -2nos-		360,000	
Security Salary -6nos-		1,080,000	
Drivers Salary-4nos-		720,000	
Gardner ,farmer,kitchen helpers salary-20nos		3,600,000	
Social Worker salary -2 nos-		600,000	
Office Staff Salary -6 nos-		1,080,000	
Cook 10, Salary-		3,000,000	
Room cleaning staff Salary -30-nos-		4,320,000	

Cloth washing staff Salary -15-nos		2,160,000	
Personnel salary for operational phase for 12 months		22,440,000	
Personnel salary for operational phase for 12 months (third year)		22,440,000	Phase-3
Grant total Rupees		1,322,440,000	