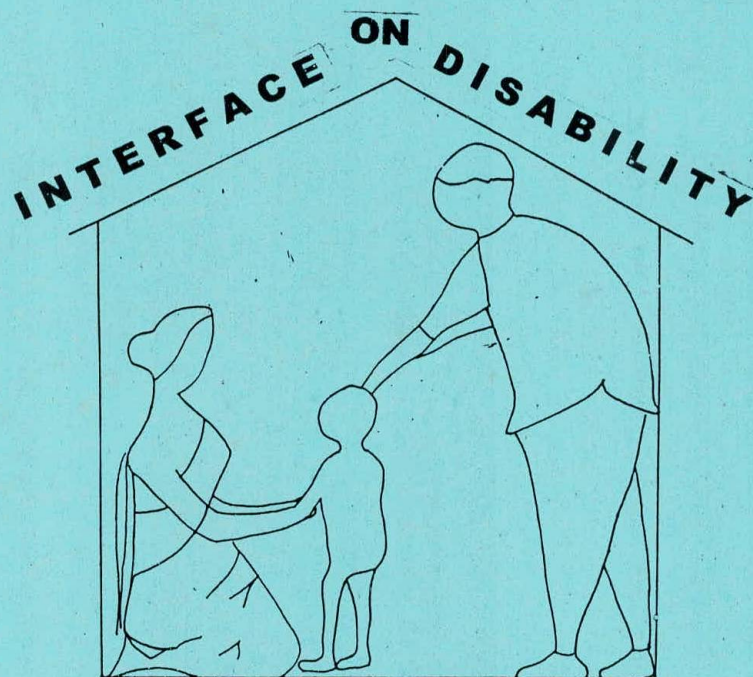


PROJECT "ID"



NGO NETWORK OF TAMILNADU



Submitted by

**THE SPASTICS SOCIETY OF TAMILNADU
CENTRE FOR SPECIAL EDUCATION
OPP T.T.T.I, TARAMANI ROAD
MADRAS 600 113**

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PROJECT ID

(Interface on Disability)

District NGO Network

A chain-linked capacity-building programme in Early Intervention covering 27 Districts in Tamilnadu.

FOR:

23 Districts NGOs, Government functionaries in the Health as well as the Welfare sectors, and Families of Young Disabled Children.

PURPOSE:

To Change Attitudes and Transfer Skills (CATS) in Childhood Disabilities to 386 Blocks in Tamilnadu.

STRATEGY:

Interfacing, strengthening, empowering and merging into existing Government and Non Govt. infrastructures.

BY:

Direct Networking between Nodal Agency NGOs in each District, Government of Tamilnadu and The Spastics Society of Tamilnadu.

1. INTRODUCTION:

Bronfenbrenner has said that

"The early childhood years are important for the simple, but sufficient reason that they come first in a dynamic process of human development. "Intervention or lack thereof, at this stage, therefore, can significantly enhance or impair the quality of life in later years. This is especially true for infants who are functioning or are likely to function, physically, mentally and/or socially below par.

SPASTN has had the privilege of evolving a Linkage Model of CBR in Early Intervention which has closely interfaced with the Primary Health Centres, ICDS, Local Youth Clubs, Mahila Mandals and Disabled persons in rural and peri-urban areas. SPASTN has successfully trained village health nurses and aanganwadi workers to do Rehabilitation work at the community level in Pudukkottai, Nilgiris and Chengelpet Districts. This training and service has been geared almost exclusively for the 0-6 yr age groups and for high risk newborns. The results have been successful and rewarding. Several thousand disabled children and families have been served in hitherto unreached areas.

2. JUSTIFICATION:

This success has led us to believe that this kind of sharing and transfer of skills in Disability Rehabilitation, to local front-line workers, is the only way of reaching and serving large numbers of disabled children of rural Tamilnadu.

This present effort is an attempt to link existing NGO efforts in every District in Tamilnadu. The aim is to build the capacity of these NGOs in Early Intervention so that they can function as Nodal Centres for their Districts. They in turn will train existing village level workers in Welfare and Health so that ultimately every village in Tamilnadu has been covered, in terms of disabled children in the age range of 0-6yrs.

3. THE OBJECTIVES OF SPASTN's EARLY INTERVENTION PROGRAMMES ARE IN GENERAL:

- a. To prevent disabilities through community awareness and education.
- b. To create possibilities for integration of the disabled in the community through awareness and understanding of their needs and problems.
- c. To detect disabilities very early.
- d. To develop local manpower through innovatively designed training programmes for parents, existing health workers (both NGO and Governmental) and interested individuals.
- e. Deliver low-cost aids, appliances, equipment as well as intervention/rehabilitation services.
- f. To design and deliver a model of community based rehabilitation in early intervention which could be replicated elsewhere in India.

4. SPECIFIC OBJECTIVES OF PROJECT ID:

1. To create positive attitudinal changes in the villages of Tamilnadu.
2. To transfer knowledge about ALL Disabilities
3. To transfer skills in Rehabilitation
4. To create a State-wide Network on Disability Prevention, Detection and Intervention.

5. SPECIFIC GOALS OF ID IN TERMS OF PREVENTION:

1. To devise strategies and intervention techniques for optimal development of the high risk infant.
2. To train and counsel parents of high risk infants for enhanced reciprocal interaction and to equip parents to become the main agents of change.
3. To undertake activities aimed at primary, secondary and tertiary prevention of childhood disabilities, through:-
 - a. through public awareness and education
 - b. tracking and monitoring of high risk mothers and infants
 - c. through coordination with TBAs (Traditional Birth Attendants)
 - d. through increasing opportunities for early detection by training of GRWs (Grassroot level workers) in early detection

In the final analysis, the concerted effort will be towards REDUCING THE OCCURENCE OF NEW INSTANCES OF PREVENTABLE CHILDHOOD DISABILITIES.

6. POPULATION SERVED:

Total Population of Tamilnadu = 55,638,318

7. DISABLED POPULATION:

General rate of incidence	=	3% of total population
3% of 55,638,318	=	1,66,914.9 disabled persons
Of this, 40% will be children	=	6,67,659 Disabled children

8. DURATION OF TRAINING:

4 Weeks	(20 working days, 6hrs a day)	for NGOs - Phase II
4 Weeks	(20 working days)	for GRWs - Phase III

9 IMPLEMENTATION:

It is proposed that the training for Phase II will be conducted on one location

- (1). At SPASTN's Taramani Centre

10 NETWORKING AND CAPACITY-BUILDING OF NGOS:

(a). In the first phase, a 2-Day Workshop of 23 District Level NGOs (each representing one District) will be held in SPASTN'S Taramani Centre.

(b). In the Second phase,

-- 2 Persons from each NGO who are qualified Rehabilitation Professionals will be trained at The Spastics Society of Tamilnadu.

11. TRANSFERRING SKILLS AND KNOWLEDGE TO EXISTING GRASSROOTS WORKERS IN HEALTH & WELFARE:

(c). In the 3rd phase,

-- AWWs of each ICDS Project, along with VHNs, ANMs, TBAs, TINIP workers, school teachers, nurses, doctors, parents and all those interested in working with disability will be given a formal and structured training course of 4 weeks by group (b).

FINALLY, these skills will be transferred to the Families of Disabled Children in the Rural areas of Tamilnadu.

(d). Course Curriculum includes:

1. Disability Prevention, Causes, Types.
 2. Child Development - Typical and atypical
 3. Assessment and Program Planning
 4. Visual Impairment and its management
 5. Hearing and Speech Impairment and its management
 6. Physical Impairment and its management
 7. Mental Impairment and its management
 8. Epilepsy and its management
 9. Strengthening families
- ALL Disabilities will be covered

(e). Medium of Instruction - Tamil

(f). Materials Developed-

1. Poster (both in Tamil & English)
2. Prescreen Wheel (both in Tamil & English)
3. Prevention Plus (both in Tamil & English)
4. Parents' Questions on C.P. (both in Tamil & English)
5. Early Intervention in CP (both in Tamil & English)
6. Compilation of Readings in Special Education (English only)
7. Video Cassette on Newborn Assessment (English only)
8. Assessment Kit (to go with the cassette)
9. Training Manual for frontline workers (English & Tamil)
10. Silent Supporters (illustrated appliances for the disabled - English only)

(g). Methodologies - Role Play, Group Discussion, Demonstrations, Lectures, Debates and Interviews with Disabled Persons and Mothers.

12 ULTIMATE TARGET GROUP

Population of Tamilnadu	-	55,638,318
General rate of incidence 5%	-	27,81,915.90
40% will be children 0 - 15 yrs	-	11,12,766.36
Of this 50% will be 0-6yrs	-	5,56,383.18

13 KEY INDICATORS OF PROJECT SUCCESS:

1. Increased number of mild to moderately disabled children screened, assessed, integrated/referred, as a ROUTINE SERVICE by Health, ICDS and TINIP personnel.
2. Number of children with severe disabilities/delays and their families, served at home.
3. Number of existing Health and Welfare personnel trained/oriented in Prevention, Early Detection and Early Intervention.
4. Number of persons reached through direct and indirect awareness programmes in the communities.
5. Number of Village Rehabilitation Committees and Self Help Groups, Disabled Adult Groups etc. constituted.
6. Involvement of disabled people in the ID programme, as well as in advocacy on behalf of inclusion in education, employment, and social life.
7. Changes in community behaviour towards persons with disabilities.
8. Reduced incidence of childhood disabilities.
9. Enhanced capacities of Nodal Agencies at the District Level vis a vis Early Intervention through CBR strategies.
10. Development of SPASTN as a Centre of Excellence in Training, Research and Resource on Prevention, Early Detection and Early Intervention.

11. Expansion of NGO Network to include every NGO working in the field of disability in Tamilnadu.
12. Documentation and Evaluation of ID.
13. Capping achievement - replication of ID model in other States/Union Territories in India.

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1.4 INDIRECT BENEFICIARIES:

It is envisaged that low-cost playgrounds for disabled children will be established in the villages; here even non-disabled children in the communities will be invited to play, thus creating a positive feeling towards disabled children. This will make integration easier as well as promote the all-round development of non-disabled children in the communities.

Similarly, organisation of Sports Days, Family Picnics, Fancy Dress competitions and other Community activities will include ALL groups of children, and families too. This will eliminate the sense of isolation and alienation that families of disabled children often experience in the communities. Thus, there will be more cohesion in the community; and families and communities together will develop greater sense of empathy and understanding which will help in creating a climate of equalisation of opportunities for disabled persons.

1.5 ROLE OF CATALYST

Our experience has shown that aanganwadi workers and health workers take pride in their new-found knowledge about Disability and their skills in Rehabilitation. Earlier, these were gaps in their knowledge-menu. With these additional skills they can (a) impart training to family members in the child's home during her routine visit (b) organise integration in schools etc. (c) and refer to the right centres for problems that cannot be met at the community level. It is estimated that 70% of the need of CWD will be met at the community level; only 30% would need to be referred outside. This referral could be to the Nodal agency in the District or to the Coordinating agency, SPASTN.

Information Booklets on concessions and schemes of the State and Central Government will be filtered down to the community and the families through the village health nurses and the aanganwadi workers.

1.6 A NOTE ON THE STRATEGY:

The unrealised aim, of all concerned, is to reach young disabled village children in the rural and remote areas of India. Clearly, we do not have the wherewithal to establish a huge new infrastructure to serve this population, now or in the foreseeable future. The only alternative is to reach them through existing functionaries, who are in close touch with the communities as part of their current routine work, for eg. Village Health Nurses and ICDS Aanganwadi Workers. In the strategy used by ID, these Government functionaries will be empowered through training in rehabilitation skills to do the following:-

1. Create awareness about childhood disability (as a preventive tool)
2. Change community behaviour on behalf of persons with disability (attitudinal change)
3. Screen, and assess CWD in the 0-6yrs population and train family members or other disabled persons in simple management techniques (through transfer of skills in Rehabilitation)
4. Most importantly, -- to include disabled persons, individually and in groups, to take on the responsibility for rehabilitation work in their communities.

These converts to Rehabilitation can become very active catalysts and agents of change in the community. They can network with youth groups, mahila mandrams and above all with disabled adults, to participate in the process of Rehabilitation.

Above all, this Projects aims at Demystification of Rehabilitation Science and makes it into an ordinary, everyday, routine skill.

It also seeks to breaks myths about Disability which are the biggest barriers to inclusion at the community level.

17. PROJECT MANAGEMENT:

SPASTN's overall policy making is through a group of dedicated volunteers who constitute an Executive Committee (see AGM Report for list).

The technical, administrative and financial reporting of all staff members (approx. 120) is through a structured Organogram with a Director at the Heads in the present context the Director is Mrs. Aloka Guha.

ID PROJECT PERSONNEL:

- Honorary Director (Director, SPASTN)
- One full time Coordinator - Mr. P.Moorthy (P.G. Diploma in Special Education and Masters in Social Work)

Resource Persons for NGO Training

- | | |
|-----------------------------------------------------|--------------------|
| - 1 Senior Special Educator - Mrs. Lakshmi P. Sarma | |
| - 1 Physiotherapist | - Mrs. Hema Vasugi |
| - 1 Psychologist | - Mrs. Usha |

EXPECTED OUTCOME:

- Information on Services, knowledge about Disability and skills in Rehabilitation to reach every district in Tamilnadu (6-8 Blocks every year)
- Increased awareness about Disabling conditions to help in reducing the incidence of new cases of avoidable childhood disabilities.
- Reduction in the severity levels of disabled children through early detection and early intervention
- More 'able' conditions to ensure better integration/inclusion into regular school programme.
- Reduced load on more expensive Rehabilitation through Medical, Vocational and Special Education Centres
- Reduced stress on families

- More socially integrated persons with disabilities.

JUSTIFICATION FOR REQUESTING SUPPORT:-

This Project will seek to:-

- Build the capacities of 23-25 NGOs in Prevention, Early Detection and Early Intervention.
- Converge Health and Welfare services at the community level
- Strengthen existing infrastructures rather than set up new ones.
- Reach Families of disabled children in hitherto unreached rural and remote areas.
- Aim at Prevention, Early Detection and Early Intervention
- Utilize the strategies of CBR, Networking and capacity-building of GOs & NGOs simultaneously.

We believe that all of these principles on which ID is based, are in total convergence with the objectives and concerns of most Donor agencies.

HOW WILL SUCCESS BE MEASURED:

1. Number of persons trained in the NGO and in the Government Health and Welfare sectors.
2. Number of children screened in the 0-6yrs age group
3. Number of persons reached through direct & indirect awareness programme.
4. Number of children with disability/delays served and their families
5. Number of disabled children included in the regular school curriculum

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6. Number of villages reporting lowered incidence of disability.
7. Number of villages routinely reporting and investigating Disabled persons in their regular Health/Welfare work.

OTHER FUNDING SOURCES:

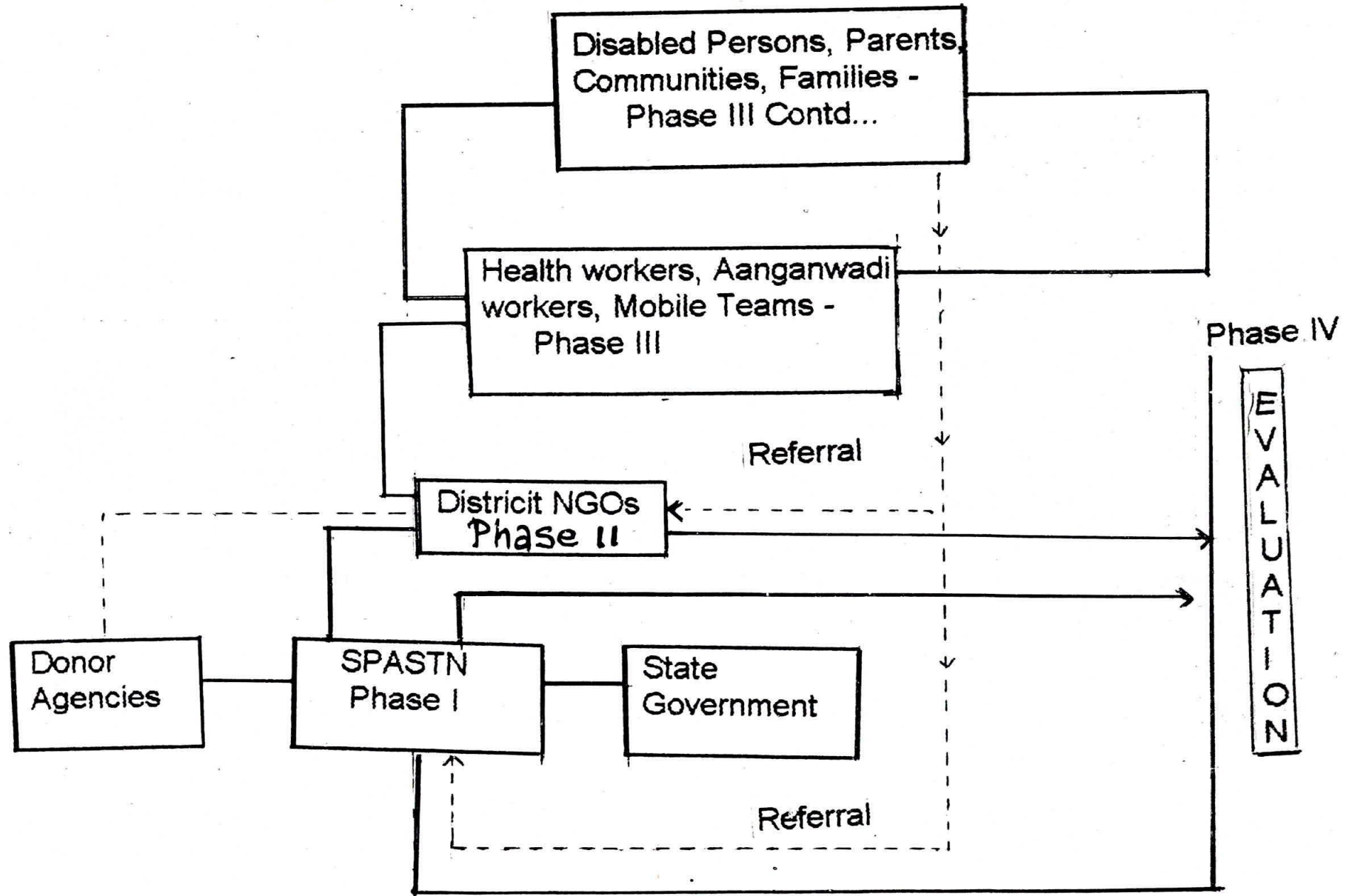
UNICEF - Madras

SIDA/Government of Tamilnadu

Rajiv Gandhi Foundation /Save the Children Fund /Australian High Commission
have shown definite interest.

This project will reach all categories of Disabled Children and all severity levels also.

ID FLOW DIAGRAM



STEP BY STEP TRANSFERENCE OF SKILLS

BUDGET PER YEAR PER DISTRICT:

1. Administrative Work & Report Writing	:	Rs. 3,500.00	
2. Food & Accomodation	:	Rs. 1,16,600.00	
3. Miscellaneous Expenditure	:	Rs. 2,000.00	
4. Training Material	:	Rs. 38,700.00	
5. Staff Salary	:	Rs. 15,000.00	
TOTAL	:	Rs.1,75,300.00	per year

PER YEAR RS.1,75,300.00
FOR 3 YEARS = 1,75,300 x 3 YRS = RS. 5,25,900.00

20. CONCLUSION:

Evidence is emerging that an investment in young children will also return monetary dividends in the form of decreased subsequent need for such costly services as special education, custodial care, welfare support and in house treatment for delinquent behavior.

"The next generation is our hope for the future, our greatest investment; in any portfolio there are assets and liabilities; today's loss can be made into tomorrow's profit; the purpose of watching our investments is to ensure that they grow" - Dr. Mervyn Fox.

This transfer of skills in Early Intervention is the best investment that we can make today. This Project is all about CATS - Changing Attitudes and Transferring Skills.

THANK YOU

STEERING COMMITTEE FOR ID

1. NORTH : Worth Trust, Katpadi, North Arcot
2. SOUTH : Helen Keller Institute for the Blind, Madurai
3. EAST : The Spastics Society of Tamilnadu, Madras
4. WEST : Rural Development Organisation, Nilgiris
5. CENTRAL : The Spastics Society of Tiruchirapalli,
Tiruchirapalli

* Districts covered under each of these regions:

- NORTH : Dharmapuri, Tiruvannamalai Sambuvarayar,
North Arcot, Salem
- SOUTH : Madurai, Kanyakumari, Tirunelveli,
V.O.Chidambaranar, Kamarajar, Ramanathapuram
- EAST : Madras, Chengai MGR, South Arcot,
Villupuram Ramasamy Padayatchiar,
Nagai Qaid-E-Milleth
- WEST : Nilgiris, Coimbatore, Periyar, Dindigul
- CENTRAL : Tiruchirapalli, Thanjavur, Pudukkottai,
Pasumpon Muthuramalinga Thevar

LIST OF PARTNER NGOS

1. MR. EDAIYUR R. MANIMARAN,
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