

# **Enabling the Disabled**

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## **FOREWORD**

The problems of the mentally handicapped have received very slight attention in our country. At a conservative estimate of one percent, we can expect as many as ten million people in the country to be suffering from some degree of mental handicap. Such a colossal problem needs a concerted and integrated effort to provide at least minimal facilities, and in this context not only must the Central and State governments be much more responsive than they have been so far, but NGOs will have to play a major role.

Dr Thakur V. Hari Prasad, who is now Chairman of the Rehabilitation Council of India, a statutory body, has been a pioneer in this field. His Institute of Research and Rehabilitation for the Mentally Handicapped based in Hyderabad has for three decades served the cause of special education, rehabilitation and vocational training. The Delhi Society for the Welfare of Mentally Retarded Children in Delhi, popularly known as Okhla Centre, of which my wife has been president for last three decades, has also done useful work in this field as have for number of other NGOs around the country.

I welcome this selection of articles and speeches by Thakur Hari Prasad in a book form, which will be a valuable document for all those interested in the welfare of the mentally handicapped. I convey my warm greetings to Thakur Hari Prasad and his associates, and have pleasure in commending this book to interested readers in India and abroad.

*Karan Singh*  
**Karan Singh**

13 April 1999

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# PREFACE

This volume presents a selected collection of the Articles written and speeches delivered by Dr. Thakur V. Hari Prasad, Founder President, Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped, Chairman, Rehabilitation Council of India, President, Rehabilitation International - Indian Chapter, President, National Forum for Welfare of the Mentally Handicapped and President, A.P. State Council for Child Welfare. Hari Prasadji needs no introduction to all those engaged in research, training and rehabilitation in the field of mentally handicapped in particular and the field of disability in general.

To merely say that Thakur Hari Prasad is a person or a social worker or social scientist par excellence is gross understatement. He exudes spontaneity, naturalness and rare innocence which enhances his appeal. Over the past three decades, he has been crusading for and on behalf of the disabled to advance their cause, to secure for them their legitimate rights as active and fully participating members of the society. His unquenchable enthusiasm, dynamism, idealism, scientific vision and untiring missionary zeal have made the scene of 'care of the disabled' undergo a revolutionary transformation. His major contribution towards the Policy Development on Mental Retardation in particular and disabilities in general at the National level is very significant in the annals of disability movement in India.

He has been a moving spirit behind the enactment of significant legislations, establishment of a number of institutions, evolution of innovative, yet pragmatic strategies and programmes concerning welfare of the disabled. His notable successes in this regard have won for him a lasting, respected and loved place in the hearts of policy makers, professionals, individuals and institutions, Non Governmental Organisations and above all those of the disabled persons themselves. Hari Prasadji is a reformer, a social activist, a visionary, a missionary, a leader and above all a humane personality, all rolled into one.

His successes have not come his way easily. The mental retardation in his eldest son has given a revolutionary, an activist, a social scientist and a unique leader to the field of mental handicap. His role as a spokesman for persons with mental handicap at an international level far supersedes his role of only as a parent. All those personal qualities have been woven together with untiring efforts at various levels and in various corners over a long period of

nearly four decades. One has to spend only a few minutes with him to get a glimpse, of his vision for the future of the disabled in general and the mentally handicapped in particular.

In short Thakur Hari Prasadji can be described as a person with immense courage, conviction and commitment to enrich the field of mental retardation in all possible ways. It is rare to encounter a person with such undeterred enthusiasm, still eager to learn and to assimilate more from contemporaries and even professionals with limited experience. It is quite fitting to acknowledge the predictive and instructive nature of the scientist that dwells deep into this activist who has established the status of care for Mental Retardation in the country to march ahead to more meaningful targets. No doubt Thakur Hari Prasadji and the Thakur Hari Prasad Institute have won many awards and received acclaim at the national level We at the THPI present this to our readers with hope in our hearts that this volume will contribute to the array of scientific works presented in the field of rehabilitation.

We express our deep sense of gratitude to Dr. Karan Singh for writing a Foreword for this volume. The Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped could not have thought of a more suitable person for this purpose.

We are grateful to Dr. Thakur V. Hari Prasad, Chairman, Rehabilitation Council of India and President, Thakur Hari Prasad Institute for being a constant source of inspiration, support and motivation in enabling us to achieve whatever success we have achieved in the field of rehabilitation of persons with mental handicap.

A number of members of THPI family have taken an active part in bringing out this publication. We express our thanks to all of them.

Prof. E.G. Parameswaran  
and  
THPI family

# A Brief Biography of Dr. THAKUR V. HARI PRASAD

Dr. Thakur V. Hari Prasad has in him a blend of a visionary and an activist as far as developmental programmes for deprived sections of the human population are concerned. His involvement in programmes and projects for human development span the wide horizon of National and International boundaries. His concern for people in need of qualitative services encompasses the individuals and their families as integral members of the society. His contributions in varied fields have made for unprecedented betterment of services and of innovative programmes resulting in improvement in the quality of life of the mentally retarded.

As a social activist, the deprivation and discrimination meted out to women and children have motivated Dr. Thakur V. Hari Prasad to undertake for the first time **Demonstration Pilot Project for Child Development** in the state of Andhra Pradesh. The project was instrumental in ushering in better maternal and child care facilities. The field-based experience of implementing the pilot project culminated in his efforts for drafting of a **National Policy for Child Development** for the country in 1964. This initiative for the first time focussed the attention of the nation's planning process on the most precious assets of the nation – 'Children' – human capital. As a sequel to the policy document presented by Dr. Thakur V. Hari Prasad, the Planning Commission earmarked for the first time after independence a sum of Rupees Three crores towards Child Development programmes in the country. The allocation has grown in subsequent 5 year plans with substantial leaps in each plan period.

As a parent of a young person with Mental Handicap, Dr. Thakur V. Hari Prasad is very empathetic with the needs, strengths and potentials of similar families. The scientist in him explores the cross-cultural, universal problems of families in relation to their role in their own communities. He has travelled extensively globally and has participated, addressed, deliberated, presented papers, chaired important sessions in many an international, inter-regional, conferences and seminars.

As an advocate of **cost-effectiveness and cultural-relevance** of service models, Dr. Thakur V. Hari Prasad has in many international forums, presented the initiatives of THPI for international replication even in developed countries. He has also invited many internationally renowned professionals as resource persons for workshops and seminars at Hyderabad attended by delegates from all over the country. **He believes in a borderless world for solving problems of persons with disabilities.**

His concern for the disadvantaged, particularly the rural people resulted in the devising of a plan to reach thousands of persons with Mental Handicap and other disabilities and touching the lives of their families with the awareness that something can be done to improve the lives of their son / daughter with Mental Handicap. The communities have been sensitised, local available resources mobilised for organising, conducting and sustaining the efforts of camps.

Dr. Thakur V. Hari Prasad is a strong believer in mass transfer of technology and skills for promoting rehabilitation services in developing countries. He is the **first non-official** to be nominated as **Chairman of the Rehabilitation Council of India**. Immediately on taking over the chairmanship, he has initiated a National Level Training Programme called the **National Bridge Course** in October, 1998 to provide a one-time opportunity to personnel who are working in the field but have not had any formal training for updating themselves. The Bridge Course of one month duration has the scope of training several thousands of in-service personnel annually, so that the backlog of untrained personnel at grassroot level in the community can be cleared within a couple of years. A similar **Bridge Course for Primary Health Centre Doctors** has also been envisaged, which will equip the health personnel in rural areas with knowledge and skills for early detection and referral for interventions. This initiative of strengthening existing human resource by updating their knowledge and skills on such a gigantic scale will probably witness the dawn of a new century with more competent personnel and professionals, who are already motivated to serve, to meet the rehabilitation needs of people with disabilities.

Dr. Thakur V. Hari Prasad has motivated his team to explore possibilities of integration of persons with Mental Handicap into the main stream of society. Many models for total vocational, functional and social integration, partial integration and inverse integration in play,

camps, Co-curricular activities at schools have been introduced and the findings are quite encouraging with scope for replication in other parts of the country.

A staunch advocate of protection of Human Rights of Persons with Mental Handicap, he has been a spokesman for the cause, organising many rallies, meets for arousing public interests. As a measure to confer right to health, he organises regular total health care camps and issues **Health Care Cards for Persons with Mental Handicap** for free treatment in collaboration with a Corporate Hospital.

The messages of Dr. Thakur V. Hari Prasad are meaningful and hold good for posterity. He advocates the need for a human touch in all efforts related to providing services for people who are in dire need. His contributions have received national and international acclaim. Rehabilitation services for persons with disabilities in India owe a great deal to his visionary and visionary zeal of Dr. Thakur V. Hari Prasad that have been operationalised into policies, programmes, service models, research projects, training component and Seminars or Workshops. He thinks globally and promotes initiatives that are culturally relevant and nationally viable. He believes that services for human beings must not deviate from ethics and eternal values. As each day unfolds, he wakes-up to a new mission that is ahead of him. His journey towards realising his vision continues with a rare combination of down right pragmatism and a long term vision as a doer and philosopher in one.

# *Special Education*

# Special Education in India

## Introduction:

The origin of Special Education in India can be traced to the era of 'Gurukula' education which adhered to fundamental principles of Special Education like...

- a) Determining the Strengths and needs of each pupil
- b) Individualization of Teaching targets and methods to match the skills and interests.
- c) Preparing the pupils for meeting the societal expectations of their prospective roles.

The versatile 'gurus' churned out illustrious administrators, valiant warriors and pious priests of students based on their socio-cultural background and capabilities. We can encounter many valued roles assumed by people with disability in our epics and scriptures where many need-based support networks have been mobilised to foster a positive social status and dignity for them.

However, the study and care of Mental Retardation has not taken any great strides in the past because it is and it still remains one of the least understood and the most misinterpreted condition among all disabilities in the country. But the social system in India has not totally isolated or confined them to a world of segregation as it prevailed until a few decades back in many developed countries. At the same time the quality of 'participation', the nature of 'interaction' and the scope of 'integration' in the mainstream of social life has been ambivalent for people with M.R. in the country.

The realisation of the efficacy of Special Education as a preventive, promotive, corrective and cost-effective modality to empower persons with Mental Retardation, has gained credence over the past half a century. Every milestone in the journey of development of special education ever since, has left an impressive impact on the efforts of adaptation and to indigenisation of the process and the practice.

This paper reviews the metamorphosis of Special Education of persons with Mental Retardation in India. It aims at highlighting specifically how special education today strives to cater to special learning needs of several million persons with Mental Retardation in a large country with multi-lingual diverse cultures through a multi-disciplinary approach. It also analyses the future of special education as a crucial rehabilitation process.

## **Status of Mental Retardation in India:**

Tentative estimates based on sporadic surveys indicate that 2% to 2.5% of the national population is afflicted by Mental Retardation. Nearly 75% of the Indian people live in rural areas. The exact enumeration of people with mental retardation in the country has not been established owing to the enormity of the task of surveying a large and populous nation as India.

*The barriers to nation-wide rehabilitation programmes are:*

- a) Low levels of awareness at all levels
- b) Inaccessibility for the people in remote areas to and by services
- c) The high concentration of services in urban areas only.

Despite the challenges of a need for large and widespread coverage of target groups, resource constraints, limited awareness, cultural - linguistic disparities, evolution of Special education and other strategic issues to promote its growth have kept pace with the global trends, while concurrently enhancing its sensitivity to the needs of the nation.

## **A Peep Into the Past & Contemporary Issues:**

Reports on experiences of families clearly indicate that the child rearing practices followed in joint families included many early childhood education opportunities for children in general. The developmentally-delayed children identified by older members of the family received most of the multisensory stimulation through traditional management practices like massages, music, chanting of holy verses, and use of toys or learning aids (rattles, rocking-horses, walkers, folklore, stuffed toys, clay modeling, water or sand play).

The rural 'Pathasala' (Day School) or the 'Gurukul' (residential learning centre) gave due emphasis to a child-centered approach, by identifying the learning channel and pace of each learner and by individualising both the teaching and learning process. The teacher in both types of education designed the curriculum to offer utility and durability to the learning on a long term perspective but dispensed it according to the functional proficiency or deficits in the learner. Thus the system of education could cater to the educational needs of a wide range of learners - the highly gifted to the sub-average. The teacher was also very familiar with the socio-cultural economic background of each student. It enabled the drafting of an appropriate curricula.

The alienation of the learner with special needs crept in when efforts to standardise general curricula with specificity in the duration of coverage and the content was introduced. The emphasis shifted from the importance of the child and its educational needs during the

24 hours of interaction with different social situations to a highly academically loaded curriculum and rigid evaluation procedures.

Scholastic backwardness is a very normative phenomenon encountered in the developing countries with low-levels of literacy. Therefore persons with mental retardation in India received inclusion into the group of academically non-achieving or deprived sections of the population. Many of them even today have access to opportunities like paid work, marriage and parenthood with the help of appropriate net work of social support. Though they are far behind their peers, they have been provided some learning experiences at home, or at the community to develop skills and independence. However the statement cannot be generalised at a National Level.

In India, like other developing countries, early detection of Mental Retardation has not been achieved at the National level. It is not infrequent to encounter a first time detection of a child at 11 or 12 years of age. Often the early formative years of education of such children have been lost in attending the general education in the mainstream which was not sensitive to their special needs or they have been kept at home with no access to education. They have also been cast into very negatively – charged stereotypical attributes due to misconceptions on Mental Retardation. Therefore any form of post-detection education is compelled to shoulder the responsibility of facilitating a positive attitude in the family and community. It must also provide learning environments and experiences that promote the independence, inclusion in community and the income generation potentialities of the pupil.

The large number of pupils in the mainstream schools, non-flexibility in an academically - oriented curriculum, negative teacher attitudes, poor ethos in school administration, lack of support services, low levels of awareness, resource constraints have collectively denied inclusion of persons with M.R. into the realm of “education” in its real sense for a long time. A chronological report of the cutoff time of the traditional teaching practices and the advent of restrictive general education in the country is not available because the transition was a very gradual process and even to date both these practices coexist in some parts of the country along with some highly scientific special educational service models in other parts.

### **Brief History of the Evolution of Special Education Services in India:**

Special Education services in India have evolved over a long period and in this process one may discern the following:

#### **Phase - I**

An awakening to the prowess of Special Education as preventive, corrective, promotive and effective rehabilitation process, sensitised many NGOs to lookup to the Western World for the technology and its application. Some NGO's initiation is reported in India during the

1940's. When viewed retrospectively it cannot be asserted that the efforts were systematic or that they were multidisciplinary inputs to meet the challenges of heterogeneity and multiplicity of the needs of those who availed the services. They served more as day care and respite centres or as remedial education centres which tried intensively to impart the '3R's to its pupils, who have been sieved away from the mainstream.

## **Phase - II**

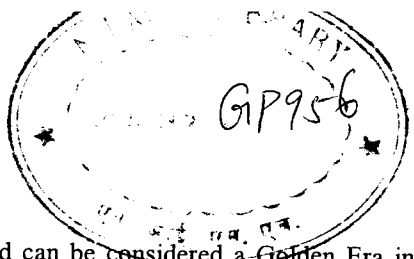
During the late 1960's and the 1970's the parental pressure, the scientific temperament of some social scientists and the global developments in special educational practices resulted in establishment of many special schools by Voluntary Organisations in India. These services explored the ways of providing multidisciplinary interventions with full-time or part-time staff and also strove to offer a meaningful need-based child-centred education which met the physical, social and emotional needs of the pupils. However there prevailed a clear compartmentalisation between Clinical interventions and class room activities in the initial stages of the multidisciplinary programming. The Special Teacher identified some domains for learning like self care, motor skills, communication and academics. It was during the early 1980's that technology was adapted to explore the possibilities of incorporating the therapies in the curricular or co-curricular programmes of the class rooms. There were other innovative changes in the process by adopting some guidelines for teacher-pupil ratio, grouping of students in appropriate age groups and developing culturally relevant curricula.

## **Phase - III**

Many organisations introduced individualisation of programmes with guidance from the multidisciplinary team. The systematic training programmes clearly revealed the necessity to involve families as informants, co-therapists and as a major link in generalisation of training into the community of all age and levels of training. Multidisciplinary Special Education strategies, which remained confined to the clinical settings, then the class rooms in special schools, thus got transferred to the families through parent-training programmes, home visits and regular parent-school links.

It was after the International Year of the Disabled that Governmental action at National level was initiated in the country. During the Decade of the Disabled, grant-in-aid schemes for special schools run by NGOs to subsidise their outlay on services was introduced to meet stipulated criteria or norms set by Government of India. Though it did not relieve the fiscal constraints, it supported the NGOs which were being sustained on the meagre resources available to them.

The National Institute for the Mentally Handicapped, under the Ministry of Welfare was established in 1985 with the objective of undertaking research and HRD to meet the National needs in collaboration with the NGO's of the country.



## **Current Issues:**

The latter half of the Decade of the Disabled can be considered a Golden Era in the growth and development of Special Education in India. The impetus was on improvising documentation of the teaching - learning process and case-study of each learner and periodic monitoring to evaluate the appropriateness of training programmes designed for children with M.R.

The individualisation of educational programming became more popular as an effective approach, though there were no mandatory provisions which enforced the same. Education of children with disability which remained solely a responsibility of the Ministry of Welfare, was also given due consideration in the National Education Policy of the Government of India (1986). However, there was very little provision for children with Mental Handicap in the policy which focussed on integrated education.

## **Integration:**

The concept of Integrated Education entered the realm of education of persons with Mental Retardation. Many viable models and inclusion strategies were evolved both by NGOs and the Government. The progress of the initiative was expedited by the non-availability of Special Schools in many parts of the country and efforts to locate some entry point for persons identified with Mental Retardation, within the available, accessible and affordable geographical limits and to support them there.

Even to date 'integration' implies different meanings to different people. Therefore the services range from facilitating mere physical proximity and locational integration to offering part-time or full-time functional participation in the class room activities and 'inclusion' in the curriculum through alternative modalities of teaching, evaluating and examination procedures.

'The school for all' philosophy which is being propagated in recent years, has existed in India. Irrespective of the intellectual or other learning deficits, children were admitted to many mainstream schools. The accidental integration has not been beneficial to many unsupported children with M.R. who dropped out at durations of time ranging from few days to few years. Therefore the philosophy is being studied as an effective modality by providing:

- a) Special units in ordinary schools
- b) Provision of resource rooms, itinerant teachers
- c) Inverse integration approaches
- d) Integration in nonacademic activities in neighbourhood schools.

Apart from being cost-effective, integration has bridged the gap between normal children

and children with M.R. by a clearly understanding the strengths and needs of children with M.R. by a large group of peers, their families, the mainstream school staff and the families of children with M.R. However, the multiplicity of needs and the heterogeneity in the capabilities of children with M.R. widen the dimensions of educational provisions to be contemplated upon in ordinary schools. The constraints of resources and other supports have made the realisation of even universalisation of primary education a difficult task even after five decades of independence. Therefore inclusive education needs to be perceived from different angles to determine its appropriateness for children with Mental Retardation.

Yet another effort is to upgrade the literacy - numeracy skills of those persons who have the readiness for it, to match the contents of the non-formal literacy programme which has been initiated nationally. It is expected that the training for the same will also enable inclusion of persons with M.R. in the 'literate' group of the community. The Integration of a delegation of participants with M.R. at the International Integrated and the Learn-to-Live-Together Camps was an unprecedented effort of THPI to provide new learning experiences to the children.

### **Training and HRD:**

Considering the magnitude of the need for trained special teachers for Special Schools, and also resource teachers, master trainers and the CPR and extension programmes, the Government organisations and NGOs are involved in multifaceted need-based training programmes.

The National Institute in collaboration with other NGOs has introduced an in-service and pre-service Diploma in Special Education [DSE (MR)] for Special Teachers at twenty five centers nation wide, with an intake capacity of 20 trainees each per annum.

The NGOs with qualitative infrastructural and academic facilities are striving for mass transfer of skills and knowledge and moulding the attitudes positively in primary school teachers, school administrators, parents, pre-school teachers, CPR supervisors etc., through short-term, tailor-made training programmes.

Various modes of communication like correspondence guidance, books, training manuals, workshops, symposia, press releases, video cassettes and television programmes have been utilised for training of trainers apart from direct instruction through Centre Based or extension services. Special education in recent years is aiming at reaching persons with Mental Handicap with basic multidisciplinary services by providing multicategory training and multidisciplinary intervention training to special teachers.

### **Research:**

Research in Special Education has focused both on adapting models of other countries and also on evolving indigenous modalities of training. Some areas of research that have accrued meaningful impact are...

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- Rural camps for awareness, educational assessment & educational guidance, follow-up.
- Integrated education models.
- Evolving of Documentation Tools and manuals.
- Evaluation of programme components like progress of learner, the programme management, the teacher skills and attitudes, family needs and strengths to support the training etc.
- Incorporating indigenous art forms and therapies for supplementing the training inputs for independence and inclusion.
- Extension of special educational principles to Vocational Training and other social situations.
- Impact indicators of short term and long term training programmes and orientation courses.
- Preparation of low-cost teaching devices.

**Factors which influenced the growth and development of Special Education in Brief:**

**Policy Development:**

Another major landmark in Policy Development for Rehabilitation of persons with mental handicap in India, was the preparation and presentation of the National Policy for the Mentally Handicapped on January 14th, 1988 by the Thakur Hari Prasad Institute, Hyderabad to the then Prime Minister Mr. Rajiv Gandhi. The Document was evolved as a Voluntary effort of the NGOs by organising a National Seminar on Mental Retardation in February 1987 by involving parents, professionals, representatives of different ministries, Government agencies, NGOs and members of the Planning Commission.

The said policy recommends National level programmes for proper educational assessment, educational guidance and educational placement options for persons with mental handicap. It also envisages some measure for establishment of more special schools and access to education. The constitution of an exclusive working group on disability in Planning Commission, Inter-Ministerial Committee are some of the immediate actions that followed the presentation of the National Policy.

A significant outcome of the National Policy which resulted in an effective enactment relevant to Special Education is the constitution of the Rehabilitation Council of India as a statutory body to standardise curricula for training programmes for rehabilitation professionals and workers at all levels. The Council that came into effect in September 1992, has taken stock of the existing curricula for teacher training programmes for various disabilities including Mental

Retardation and has taken upon it, the task of reviewing, evaluating, modifying, approving and standardising all existing and proposed training programmes.

As per the Indian constitution, Disability is a state subject, therefore THPI has again drafted the report of a Seminar in August 1994, recommending major issues for a State Policy for rehabilitation of persons with disability. The recommendations in the field of Mental Retardation include, access for integration in the general education system and also expediting of proposals for funding from Special Schools which are routed through the State Government.

### **Public Awareness:**

India has a fairly wide coverage of communication net work. The electronic media, radio and T.V. covers more than three fourths of the country. The language barriers in a multilingual country and differences in cultural practices pose a certain amount of difficulty in reaching the entire nation through a single-language network. The print medium is also accessible to the literate population while many illiterate people manage to obtain a transfer of information from newspapers and bulletins. Yet the media's coverage-allotment to Mental Retardation was very minimal in the past. A series of Media Seminars initiated by Thakur Hari Prasad Institute between 1991 -1992 in different parts of the country revealed that there was a paucity in availability of authentic information on Mental Retardation. It also disclosed that the non-cognisance of media is not the outcome of apathy towards the cause, but lack of awareness on the need for dissemination of awareness-material to the general public. There has been a marked 'inclusion' of Mental Retardation in all the National media. The strategy has been now adopted by the Government.

Age-old traditions and rituals which devalue people with mental handicap and subject many of them to ineffective 'healing' practices still prevail in some remote villages. Therefore the readiness of the community to channelise the residual potential of a person with Mental Retardation through Special Education is relatively limited. The empowerment of the family and the community in such cases is taken-up through folk-theatre, counselling and mass awareness programmes.

The rural camps for early detection, screening and follow-up of children with disability have also concurrently enhanced awareness on the need for appropriate training and educational facilities for the identified children. Many integrated runs and rallies by persons with mental handicap their families, professionals, service-providers, bureaucrats, involving students, youth etc., have been organised for public awareness on their right to education.

### **Effective Networking and Monitoring Mechanisms:**

Special Education of persons with mental handicap is a lifelong process. The heterogeneity in the special training needs and the functional capabilities of persons with Mental Retardation

necessitate a clear deviation from stereotyping services as a general 'category' in the policy implementation process. It requires networking at inter-ministerial level (health, education, welfare, labour etc.) interdepartmental level, and also local administration, village leaders, school administrations, multidisciplinary rehabilitation professionals, people with mental retardation, their families, and community members. The networking is essential both at Institution based centres and CPR programmes. Every link in the process has a role to play. As a group of highly vulnerable- persons, people with mental retardation require supports at every link to assert their Right to Education and training. Advocacy groups in India have come to acknowledge their Right to Equalisation of Opportunities inspite of their individuality in skills and unique needs. A time has come when it has been realised that persons with mental retardation need to be conferred the right to be different due to their special needs rather than compelling them, to cope with expectations of 'Normative Performance. Therefore appropriate support systems need to be evolved to accommodate and include them in the educational process.

It is not infrequent to encounter a wide gap between policies and practices. Special Education as a link between persons with mental retardation and their interactional experiences in the community and the national rehabilitation programmes needs regular monitoring and feed back on its directions and plans so as to ensure optimum accessibility to appropriate available facilities at affordable costs. An exclusive working group in the Planning Commission on disability was established.

The Inverse Care Law of the least availability of services to those sections, who need them the most but fail to seek it or avail it when offered, is gradually being replaced by grants for programmes where they do not exist.

In order to alleviate the malady of inappropriate interventions by unqualified personnel, the Rehabilitation Council of India is involved in registering rehabilitation professionals and workers for specific rehabilitation inputs to persons with disability. It has also framed the guidelines for professional ethics. The approval and monitoring of various HRD programmes by RCI is also expected to eliminate mushrooming of training programmes which do not meet the norms of quality.

Evaluation of special schools for approval of grant-in-aid have been followed by the Ministry of Welfare, Government of India in collaboration with the State Government machinery.

At the individual level, individualised educational programmes are being popularised in special schools, so as to monitor at regular periodicity, the training process and its impact in meeting the special needs of the learners.

Social validation of quality of special educational services, is obtained by school administrators through regular interactions with the families, caretakers or other staff involved directly and indirectly in the educational programming.

## **Role of Micro Technology, Electronics and Robotics:**

India is not totally resistant to the inclusion of Micro computer applications, or electronic media or robotics as instructional tools for people with mental retardation. However, the prohibitively high cost of providing access to this effective approach limits the availability, affordability and accessibility. Retraining of teachers is also another limitation. However the scope of the new technological appliances to reduce skill demand and to promote the learning process, retrieval of built-in data or information are ideally suited to 'educate' persons with Mental Retardation. People of India have understood the versatility of computer applications after recent computerisation of many services in the country. Technology in India which has advanced to manufacture hardware which withstand the tropical heat and dust to a fair degree is yet to be optimally sensitised to create software that will meet special educational needs of persons with Mental Retardation. Efforts have been launched in those lines recently.

The tremendous tempo in developments in the field of special education since the later half of the 1980s, accelerates the expectations of bridging this gap between the educational needs and between educational opportunities for persons with mental retardation in India in the 21st century.

## **Future Trends:**

Though no scientific futuristic studies have been reported, some predictions that are likely to emanate from observations of the past in the field of Special Education are:

- Inclusive Education will be more systematised and streamlined to meet the needs of children with Mental Retardation at least upto primary levels of education.
- More research publications on special education will emerge.
- Special schools will be established in larger numbers and will cater more to persons with severe disabling conditions, rather than to those with mild difficulties.
- The expertise of master trainers and trained teachers in special education of persons with Mental Retardation will be utilised to a greater extent for dispensing the multidisciplinary special learning needs of children in general education settings and adults in real work settings as a support for the realisation of the philosophies of 'school for all' and 'inclusion' in all social context.
- Better quality in special education services can be expected with monitoring mechanisms for IEP, pre-service and in-service training of human resource.
- CPR approaches, empowerment of families and community and the implementation of the legislative process will offer more scope for Normalization and equalisation of opportunities.

- Awareness on the educational needs, prospects and possibilities of accessing available services will improve.
- The gap between need for services and their availability will be reduced.
- An international data based on special education provisions and research will be evolved.
- India will stand a good chance of actively involving in the International Implementation Network for exchange of technology in Special Education.

**Conclusion:**

We are optimistic that appropriate technology and support systems will emerge to accommodate and include persons with Mental Retardation effectively in the educational goals of the Nation.

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# Special Education In India for the Disabled

## **Introduction:**

Globally, Special Education emerged more as an outcome of compassion and altruism for persons who were deaf, blind physically handicapped and far behind their peers than as a matter of social justice and human right as it appears today. The importance it has achieved in India as an indispensable link in the rehabilitation process is a result of consistent evolution caused by the persistent pursuits of parents, professionals and religious institutions and missionaries, many voluntary organisations and Governmental efforts.

## **Traditional Education Systems:**

The pages of ancient Indian History reveal the existence of a practical approach to individualised education programme in a residential setting called 'Gurukula'. Many students with special educational needs caused by disabilities and deprivation have been written about in our scriptures. These persons were effectively integrated in the group of normal students and participated meaningfully in the community in adulthood.

Even in day schools called 'Pathasalas', an ecology-based curriculum with individualised strategies and teaching targets was evolved, which enabled the students to transcend into the community smoothly. Many instances of prevalence of home-based education are also cited in our scriptures.

The guru took into account the ultimate adult role and also incorporated the culturally-relevant targets for teaching each pupil. A clear assessment of the pupil in totality was made through performance-based evaluations.

## **Emergence of Present Trend:**

Several invasions, influence of colonisation and the prolonged rule of British Raj, brought about changes in the educational system. Many British models of education were adopted. Thus in 1885 emerged the first school for the deaf and in 1887 the first school for the blind which was established by missionaries in India, and which replicated more the charity model advocated in the West.

Till the 1970's for over 90 years, special schools alone catered to the education of children with disabilities. The Kothari Commission (1964-66) and UNESCO in 1970's studied

the possibilities of educating children with disabilities in the existing general education system and recommended that those children who are capable of being educated in the ordinary schools should be given equal opportunity through integrated education.

In the view of the social and economic implications, UNESCO recommended that children with disabilities may be educated in the regular schools in the developing countries. It also advised developing nations to direct their national policies towards equal access to education (1973, 1977). India launched a centrally sponsored scheme of Integrated Education for the disabled in 1974. In 1987 The National Council for Educational Research and Training (NCERT), in collaboration with UNICEF introduced a Project Integrated Education for the Disabled (PIED) to strengthen the programme in 10 states and Union Territories. The project was implemented with support of aids, appliances and resource teachers. Financial assistance for teacher training, equipments, books and assessment facilities were provided. The project was implemented in Government schools only.

However, many voluntary agencies and private schools have also implemented different models of integration with special educational supports in urban settings. The THPI, Hyderabad and its Rural Project at Rajahmundry are involved in integration of children with disabilities in rural pre-schools (Balwadis) in over 400 villages in the State of Andhra Pradesh. The institute also provides social integration opportunities for older children with a Mental Handicap through partial integration in neighbourhood schools and inverse integration approaches like summer camps, at Local, National and International level. Some schools have successfully established special units in ordinary schools.

Voluntary organisations which have pioneered the cause of education of children with disability in India, even to this day are more involved in running special schools. Parents of children with disabilities are also apprehensive of sending their wards to ordinary schools for the following reasons.

1. High classroom strength which deters individualised learning experiences
2. Non-availability of trained teachers and other support service personnel.
3. Limited access to curricular and co-curricular activities of the general education.
4. Absence of guidance, counselling and programme development for families to support the educational accomplishments of their wards.

India has established effective growth and development in the field of special education over the last half century through adaptations in cross-cultural practices, indigenous approaches, research, human resource development and information dissemination. The initiatives of NGOs are being supplemented by grant-in-aid schemes and technical guidance supports of the Government.

**a) Prevalence of Disability and its Implication for Special Educational Services:**

To this date, a systematic enumeration of the number of persons with disabilities in the country has not been made. The reason being the large geographical area and the enormity of the population. Therefore clear estimates of the magnitude of the special educational needs of pre-schoolers, school going children, youth adults and senior citizens are not available. Strangely the horizon of special education is often restricted only upto the age of 18 years for persons with disabilities. 'Schooling' or attendance in a class room alone is often considered 'education' even among the literate population of the nation.

A tentative estimate of 90 million people with disability and an annual increase of 2 million has been made based on different surveys and reports available. Over 30 million of them are reportedly under 14 years of age for whom special educational services are imperative. All current and prospective schemes and programmes for special education follow this tentative estimate.

**b) Special Education Services Offered to Persons with Disabilities:**

Children and young people with disabilities are educated in segregated settings as well as in general mainstream schools. Many of them do not have access to either of the facilities are 'educated' by the families with or without professional guidance or support.

The generally prevailing policy is to refer children with severe disabling conditions to special schools and to support those with mild disabling conditions in regular schools with special educational support services. In practice, many children who could have been included with minimal supports in the regular schools are also enrolled in special schools. To many of them who have acquired entry to regular schools 'inclusion' remains a misnomer. Due to lack of appropriate support many of them drop out midway with scanty academic achievements, poor self-confidence, and inadequate preparation to cope with the challenges in the community. However it is not the universal experience. There are many voluntary organisations Missionary schools and Government schools that have provided effective learning experiences to blind and deaf children, and children with orthopaedic handicaps Mental Retardation that remains still the least understood among the general population and the academicians, has not yet been given the due impetus for effective supports in integrated education. Integration cannot follow a homogeneous approaches. The heterogeneity of people with disabilities needs to be accommodated in the available provisions. Resource constraints interfere with implementation of these principles.

The cost-effectiveness of inclusive education is not advocated in the nation at the cost of other special services which children with disabilities are entitled to. The Project Integrated Education of the Disabled, launched in 1987 under the Department of Education of Ministry of Human Resource Development has covered 12,000 schools in 17 states/Union Territories

providing integrated education to 40,000 disabled children till 1996.

The exact data on the number of special schools and the number of children availing the facility is not available though there is a marked growth in the establishment of new schools. But still around 240 districts in the country are reported to have no special schools.

### **Nature of Special Educational Services Offered:**

There is no homogeneity or universal adherence to minimum standards in service-delivery by service providers. There are exemplary organisation in the voluntary sector which offer very systematic and multidisciplinary approaches to special education with effective linkages for generalisation of education in the day to day life of the students. There also exist organisations which cater to the physical presence of the student in a class room with stereotyped training experiences and common teaching approaches. The monitoring mechanisms are involved in appropriate utilisation of grants-in-aid rather than qualitative educational experiences to children with disabilities.

Efforts to improve quality of service through evaluation of service-delivery by professionally qualified personnel has been initiated. It needs to gain momentum for a nation-wide application of minimum standards.

The proposed schemes of including persons with disabilities in the District Primary Education Programme (DPEP) for universalisation of primary education, other literacy enhancement missions, informal education programmes etc., are likely to encompass more people with disabilities into the realm of education during the IXth and Xth Five year Plan period (1998 - 2003, 2004 - 2009).

Irrespective of whether enrolled in a special school or regular schools, children who are blind, deaf and Orthopaedically handicapped are made to participate in the National Curriculum for general education. With the help of some relaxations at the curriculum content, modifications in the examination procedures, they qualify in the board examinations undertaken by their able-bodied counterparts and also some of them also enroll for higher education in universities or other technical training institutes. An individualised compensatory curriculum is also offered to them in schools to cope with the challenges of the disabling conditions.

All educational material, books, tape-recorders, tactile learning equipments, pre-recorded audio cassettes of learning material etc., are provided free of cost or at subsidised rates to them. Free residential facilities are also offered for children who are not local residents. Travel concessions and scholarships are also provided.

## **Teacher Training:**

Master trainers, trained in advanced countries invariably trained the other teachers of special schools in the past. The duration, course content, nature of training, monitoring of application of the training, frequency of refresher programmes were not uniform.

Many teacher training programmes emerged as a result of NGO initiatives. The courses varied from short term crash course, Certificate course to Diploma programmes. Later the University Grants Commission (UGC), the National Council for Educational Research and Training (NCERT) and its four Regional Centres, the National Institutes and their Regional Training Centres have also launched teacher-preparation programmes for different disabilities.

While some NGOs and the National Institutes focus on teacher preparation programmes for a single disability, NCERT is involved in the preparation of multicategory teachers for Special Education. The Universities conduct Bachelor of Education and Master of Education, courses in Special Education. Considering the importance of uniformity and relevance of the courses, the Rehabilitation Council of India - a statutory body under the Ministry of Welfare - was constituted by an enactment in 1992 which came into force in July 1993 for standardisation and approval of different training programmes.

The B.Ed., and M.Ed., courses in Special education offered by the Universities which were hitherto approved by the National Council for Teacher Education (NCTE) are now under the purview of the Rehabilitation Council of India (RCI) for approval of syllabus. RCI is contemplating on establishing effective linkages with the different Universities in the country for promoting courses in Special education and other disciplines in rehabilitation. RCI has developed forty seven training programmes of short and long term duration which also include teacher training for Special Education. A total of ninety one institutions falling both in the Government and Voluntary sectors have been recognised after an inspection of these organisations by an expert committee for conducting different training programmes including teacher preparation.

The Ministry of Education, Government of India is also making efforts to incorporate Special Education in the curriculum of regular school teacher training programme. Both pre-service and in-service training programmes are being modified to incorporate special education component into the curriculum. Many pre-school teacher-training programmes have also included "Education of exceptional children" in their curriculum. Considering the paucity of trained teachers and the large number of children with disabilities to be reached, the nation is gearing up to clear the backlog of untrained teachers in special schools and in regular schools.

A projection of Human Resource requirement for the IXth and Xth Plan phase by RCI reveals a great gap between availability of trained teachers and the number of children to be catered to. The table below reveals the numerical requirement of teachers.

Sl. No.	Field of Disability	Available trained Spl. Teachers	To be trained in 9th Plan	To be trained in 10th Plan
1.	M.R.	4,295	19,500	39,000
2.	Visual Handicap	1,079	7,500	15,000
3.	Hearing Handicap	4,011	15,000	30,000
4.	Cerebral Palsy	–	1,000	2,000
5.	Multiple Disables.	–	1,000	2,000

The projected numbers of teachers can teach more children with disabilities. The estimated number of children who would be covered by the 10th Plan phase is as follows:

Sl. No.	Type of Disability	Estimated Number of Children
1.	Hearing Impairment	3,00,000
2.	Mental Retardation	2,50,000
3.	Visual Handicap	1,50,000
4.	Cerebral Palsy	25,000
5.	Multiple Disabilities	15,000

Both the Government and Voluntary Organisation are involved in extension services for training the trainers of children with severe disabilities. Crash orientation seminars, workshops are organised for teachers of ordinary schools on different aspects of special education.

Realising the importance of early stimulation and pre-school education, many preschool programmes are being strengthened with special education supports to prepare children with disabilities for formal education readiness. Parent training programmes are also gaining more importance. Special educational supports are extended to young persons and adults for further education and training.

Individualised Education programmes have been adopted in many special schools for children with special needs. Parents of students are often consulted in framing educational goals. However, mandatory provision of IEPs as in USA is not made. Access to other therapeutic interventions and special services is not regularly provided for even by many special schools.

Non-availability of resource rooms or resource teachers are not infrequent in many regular schools which have admitted children with disabilities.

### **Resources, Access and Ethos:**

Resource constraints - both human and material -are inherent challenges to human services in a developing country. The Government of India has recognised the indispensability of NGOs for effective qualitative service-delivery. A grant-in-aid scheme which funds 90% outlay on expenditures that meet the norms set by the Ministry of Welfare is available to Special Schools run by the NGOs. The procedure for availing the grant-in-aid is cumbersome and time-consuming for the NGOs who have to concurrently strive for the 10% of expenditure to be mobilised by them. The grant-in-aid offered as salary to teachers of NGOs is far below the scale of pay of personnel on lower ranks in Government sector. This compounds the difficulty of NGOs in attracting qualified, trained resource personnel or teachers to sustain them for reasonable periods.

Some Voluntary organisations have identified innovative ways of fund-raising to supplement the part funding received from the Government. It is a bitter truth that many organisations which are motivated to provide qualitative special educational programmes are compelled to resort to soft loans or other financial assistance due to resource constraints. Some of them identify low-cost methodologies and materials for implementing their schemes without compromising on the scientific principles.

Regular schools are housed invariably in small premises. Very few private schools have the sensitivity to provide a conducive ecology and space for co-curricular and leisure activities. Special schools have appropriate infrastructure with access facilities. But it is not infrequent to find architectural barriers restricting access to optimal education of children with disabilities.

Apart from barrier to access to the physical environment many students also do not have access to information on the supports - both material and services—to promote the quality of their learning experiences, and rehabilitation. Early career-guidance, information on further education options and shaping up of work experiences at school are virtually not accessible to many of them who are on the verge of school leaving.

Attitudes towards education of disabled children are ambivalent. Priority for scholastic achievements differs in urban and rural areas. Among those in low socio economic groups,

school drop out rates are very high even among normal children and often children with disabilities are denied even exposure to schooling. Inconsistent and inappropriate management of the special needs of the children by families who are unaware of their potentials and their problems, leave them with many unexplored latent talents. Negative Community attitudes and misconceptions about disabilities add to deprivation of optimum learning opportunities.

In rural areas regular schools invariably offer access for physical integration though no special educational supports are available. But very few parents avail the opportunity. In urban areas, the Government schools do accommodate children with disabilities. However the private schools have their own apprehensions of the additional work load on their teachers. They also express concern on overall performance of the normal children due to inclusion of disabled children. Again, the non-availability of resource teachers, special materials and facilities also dissuade both the schools and the parents from admitting disabled children to regular schools. However schools that are equipped with support network do include children with disabilities. The trend to establish special units in ordinary schools for children with Mental Retardation and other severe disabling conditions is gaining momentum.

### **Linkages and Coordination:**

India is in the process of establishing effective linkages with special schools and ordinary schools to enable mutual transition of children with special needs to an appropriate least restrictive educational environment. Similarly efforts for better NGO and Government partnership are being contemplated on by the Ministry of Education, Welfare, Labour and other allied departments.

'Disability' and 'Education' are state subjects according to the constitution of India. The Government of India is involved in an exercise to implement schemes for special education of children with disabilities by involving the State Government, local administration and village authorities for an appropriate decentralisation of the service schemes. The Modus Operandi for inter-ministerial and interagency collaboration are being worked out.

### **Legislation:**

India presently has a comprehensive Legislation called Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act 1995. The Act envisages provisions for effective ways of meeting special educational needs of children with disabilities. The implementation of the Act is awaiting the framing of strategies and schemes by a core committee of experts in the field drawn from NGOs, government agencies and representatives of different government departments. The committee has met a few times in the recent past. Efforts are being made to incorporate schemes that are socio-culturally relevant and economically viable and at the same time will confer optimal opportunities for education of children with disabilities.

## **Conclusion:**

India is not complacent about the role of education as an integral and indispensable part in the developmental process of children and young persons with disabilities. Nor is the nation far behind other developing countries in evolving culturally relevant scientific approaches and strategies. Constraints of resources and the enormity of the number of persons to be catered to does create barriers in bridging the gap between intention and implementation of many programmes.

We admit that we need to catch up with many innovative techniques and technological advances practiced in other nations. But the challenge is to decide between the widening of our horizon of service-delivery vertically or horizontally i.e. to provide super special services to a manageable few or basic minimal services to a larger number of disabled children. All efforts, research and development, policies and practices are however involved in finding ways and means to eliminate the discrepancy between the need for qualitative special educational services and the availability of the same.

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# Treating disabled people as the 'Leftovers' of society loses its meaning

## **Introduction:**

It is important to stop excluding disabled people from society. They should be recognised in the dimension of human rights. Disability policy in general must therefore now move from charity and segregation to planning of active inclusion of disabled people - within the concept of a "Society for All".

Our commitment to education for all, recognising the necessity and urgency of providing education for children, youth and adults with special education needs within the regular education system endorses the **frame-work** for action on **special needs education** for the Government and the NGOs, to be guided by the spirit of implementation without further delay.

Special Education system should be flexible and provide individualised support system for children. There is enough evidence to show that to ensure the parents of children with retardation need the involvement of professionals from other fields. Special Education should respond to the diversity of children's needs and abilities including the differences in their ways and paces of learning. Special Education is team work and the responsibility should be shared by the whole school provided with support services viz., a mobile resource teacher; supply of special teaching aids and material; assistance by parents, volunteers and older students; modification and adaptation of the curriculum according to the environment and in-service training of the staff; a positive climate and a referral service.

- \* Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning.
- \* Every child has unique characteristics, interest, abilities and learning needs.
- \* Education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs.
- \* Those with special education needs must have access to regular schools which should accommodate them within a child centered pedagogy capable of meeting their needs.

- \* Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire process of education.

### **The Government should:**

- \* give the highest policy and budgetary priority to improve their education systems to enable them to include all children regardless of individual differences or difficulties.
- \* adopt as a matter of law, policy and principle, inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise.
- \* develop demonstration projects and encourage exchanges with other countries having experience with inclusive schools.
- \* establish decentralised and participatory mechanisms for planning, monitoring and evaluating educational process for children and adults with special education needs.
- \* encourage and facilitate the participation of parents, communities and organisation of persons with disabilities in the planning and decision making process.
- \* invest greater effort in early identification and intervention strategies, as well as in vocational aspects of inclusive education.
- \* ensure that, in the context of a systemic change, teacher education programmes, both pre-service and inservice, address of special needs education in inclusive schools.

### **We must call upon the international community:**

- \* governments with international cooperation programmes and international funding agencies, the United Nations Educational, Scientific and Cultural Organisation (UNESCO), the United Nations children's Fund (UNICEF), the United Nations Development Programme (UNDP), and the World Bank.  
 "To endorse the approach of inclusive schooling and to support the development of special needs education as an integral part of all education programmes".
- \* the United Nations and its specialised agencies, in particular the International Labor Office (ILO), the World Health Organisation (WHO), UNESCO and UNICEF.  
 "To strengthen their inputs for technical cooperation, as well as to reinforce their cooperation and networking for more efficient support to the expanded and integrated provision of special needs education".

- \* non-governmental Organisations-NGOs involved in country programming and service delivery:  
 “To strengthen their collaboration with the official bodies and to intensify their growing involvement in planning, implementation and evaluation of provision for special educational needs”.
- \* to ensure that special needs education forms part of every discussion dealing with education for all in various forums.
- \* to mobilise the support of organisations of the teaching profession in matters related to enhancing teacher education as regards provision for special educational needs.
- \* to stimulate the academic community to strengthen research and networking and to establish regional centers of information and documentation; also, to serve as a clearing house for such activities and for disseminating the specific results at national level.
- \* to mobilise funds through the creation from the current year of an expanded programme for inclusive schools and community support programmes, which would enable the launching of pilot projects that showcase new approaches for dissemination, and to develop indicators concerning the need for and provision of special needs education.

### **Framework for Action:**

Every person with a disability has a right to express his wish with regard to his education, as far as this can be ascertained. Parents have an inherent right to be consulted on the form of education best suited to the needs, circumstances and aspirations of their children.

- a. The schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas or groups. These conditions create a range of different challenges to school systems.

### **In the context of this Framework:**

The term ‘Special educational needs’ relates to all those children and youth whose needs arise out of disabilities or learning difficulties. Many children experience learning difficulties and thus have special educational needs at some time during their schooling. Schools have to find ways of successfully educating all children, including those who have serious disadvantages and disabilities. There is an emerging consensus that children and youth with special educational needs should be included in the educational arrangements made for the majority of children.

Special needs education incorporates the proven principle of sound pedagogy from which all children may benefit. It assumes that human differences are normal and that learning must accordingly be adapted to the needs of the children rather than the child fitted to preordained assumptions regarding the pace and nature of the learning process. A child-centered pedagogy is beneficial to all students and, as a consequence, to society as a whole. Experience has demonstrated that it can substantially reduce the drop-out and repetition that are so much a part of many education systems while ensuring higher average levels of achievement. A child-centered pedagogy can help to avoid the waste of resources and the shattering of hopes that is all too frequently a consequence of poor quality instruction and a 'one size fits all' mentality towards education.

This has led to the concept of the **Inclusive School**. The challenge confronting the inclusive school is that of developing a child-centered pedagogy capable of successfully educating all children, including those who have serious disadvantages and disabilities. The merit of such schools is not only that they are capable of providing quality education to all children; their establishment is a crucial step in helping to change discriminatory attitudes, in creating welcoming communities and in developing an inclusive society. A change in social perspective is imperative.

For a long time, the problems of people with disabilities have been compounded by a 'disabling society' that has focussed upon their impairment rather than on their potential.

*This framework for ACTION comprises the following sections:*

- I. New thinking in special needs education
- II. Guidelines for action at the national level
  - A. Policy and organisation
  - B. School factors
  - C. Recruitment and training of educational personnel
  - D. External support services
  - E. Priority areas
  - F. Community perspectives
  - G. Resource requirements
- III. Guidelines for action at the National and International level.

### ***I. Special Needs Education:***

The trend in social policy during the past two decades has been to promote integration and participation and to combat exclusion. Inclusion and participation are essential to human

dignity and to the enjoyment and exercise of human rights. Within the field of education, this is reflected in the development of strategies that seek to bring about a genuine equalisation of opportunity. Experience in many countries demonstrate that the integration of children and youth with special educational needs is best achieved within inclusive schools that serve all children within the community. It is within this context that those with special educational needs can achieve the fullest educational progress and social integration. While inclusive schools provide a favourable setting for achieving equal opportunity and full participation, their success requires a concerted effort, not only by teachers and school staff, but also by peers, parents, families and volunteers.

The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognise and respond to the diverse needs of their students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organisational arrangements, teaching strategies, resource use and partnerships with their communities. There should be a continuum of support and services to match the continuum of special needs encountered in every school.

Within inclusive schools, children with special educational needs should receive whatever extra support they require to ensure their effective education. Inclusive schooling is the most effective means for building solidarity between children with special needs and their peers. Assignment of children to special schools or special classes or sections within a school on a permanent basis should be the exception, to be recommended only in those infrequent cases where it is clearly demonstrated that education in regular classrooms is incapable of meeting a child's educational or social needs.

The situation regarding special needs education varies enormously from one place to another. There are, for example, some well established systems of special schools for those with specific impairments. Such special schools represent a valuable resource for the development of inclusive schools. The staff of these special institutions possess the expertise needed for early screening and identification of children with disabilities. Special schools can also serve as training and resource centres for staff in regular schools. Finally, special schools or units within inclusive schools - may continue to provide the most suitable education for the relatively small number of children with disabilities who cannot be adequately served in regular class rooms or schools. Investment in existing special schools should be geared to their new and expanded role of providing professional support to regular schools in meeting special educational needs. An important contribution which the staff of special schools can make out the ordinary schools is to match the curricular content and method to the individual needs of pupils.

Countries that have few or no special schools would, in general, be well advised to concentrate their efforts on the development of inclusive schools and the specialised services needed to enable them to serve the vast majority of children and youth—especially of providing teacher training in special needs education and the establishment of suitably staffed and equipped resource centers to which schools could turn for support. Experience, indicates that the high cost of special schools, means in practice, that only a small minority of students with disabilities usually an urban elite, benefit from them. The vast majority of students with special needs, especially in rural areas, are as a consequence provided with no services whatsoever. **It is estimated that fewer than one per cent of children with special educational needs are included in existing provision.** Experience, moreover, suggests that schools, serving all of the children in a community, are most successful in eliciting community support and in finding imaginative and innovative ways of using the limited resources that are available.

In the past relatively few children with disabilities have had access to education and therefore, there are millions of adults with disabilities who lack even the rudiments of a basic education. A concerted effort is thus required to teach literacy, numeracy and basic skills to persons with disabilities through adult education programmes.

It is particularly important to recognise that women have often been doubly disadvantaged because of the gender bias, compounding the difficulties caused by their disabilities. Women and men should have equal influence on the design of educational programmes and the same opportunities to benefit from them. Special efforts should be made to encourage the participation of girls and women with disabilities in educational programmes.

## *II. The Guidelines for action at the national level:*

This “**Framework**” is intended as an overall guide to planning for action in special needs education. It evidently cannot take account of the vast variety of situations encountered in the different regions and countries of the world and must, accordingly, be adapted to fit local requirements and circumstances. To be effective, it must be complemented by national, regional and local plans of action inspired by a political and popular will to achieve education for all.

Integrated Education and Community Participative Rehabilitation - CPR represent complementary and mutually supportive approaches to serving those with special needs. Both are based upon the principles of inclusion, integration and participation, and represent well-tested and cost-effective approaches in promoting equality of access for those with special educational needs. We should recognise the principle of equality of opportunity for children, youth and adults with disabilities in primary, secondary and tertiary education carried out, as far as possible, in integrated settings. Parallel and complementary measures should be adopted in the fields of health, social welfare, vocational training and employment in order to support

and give overall effect to educational legislation.

### **A. Policy and organisation:**

Educational policies at all levels, from the national to the local, should stipulate that a child with a disability should attend the neighbourhood school that is, the school that would be attended if the child did not have a disability. Exceptions to this rule should be considered on a case-by-case basis where only education in a special school or establishment can be shown to meet the needs of the individual child.

**Mainstreaming:** The practice of 'mainstreaming' children with disabilities should be an integral part of national plans for achieving education for all. Even in those exceptional cases where children are placed in special schools, their education need not be entirely segregated. Part-time attendance at regular schools should be encouraged. Necessary provision should also be made for ensuring inclusion of youth and adults with special needs in secondary and higher education as well as in training programmes. Special attention should be given to ensuring equality of access and opportunity for girls and women with disabilities.

**Care for Multiple Disabled:** Special attention should be paid to the needs of children and youth with severe or multiple disabilities. They have the same rights as others in the community to the achievement of maximum independence as adults and should be educated to the best of their potential towards that end.

**Deaf/Blind Care:** Educational policies should take full account of individual differences and situations. The importance of sign language as the medium of communication among the deaf, for example, should be recognised and provision made to ensure that all deaf persons have access to education in their national sign language. In view of the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in special schools or special classes and units in ordinary schools.

**Community Participative Rehabilitation:** should be developed as part of a strategy for supporting cost-effective education and training for people with special educational needs. Community level rehabilitation should be seen as a specific approach within community development aimed at rehabilitation, equalisation of opportunities and social integration of all people with disabilities; it should be implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate education, health, vocational and welfare services.

**Administration:** Both policies and financing arrangements should encourage and facilitate the development of inclusive schools. Barriers that impede movement from special to regular schools should be removed and a common administrative structure organised. Progress towards inclusion should be carefully monitored through the collection of statistics capable of revealing

the number of students with disabilities who benefit from resources, expertise and equipment intended for special needs education as well as the number of students with special educational needs enrolled in regular schools.

**Coordination:** Coordination between educational authorities and those responsible for health, employment and social services should be strengthened at all levels to bring about a convergence and compatibility. Planning and coordination should also take account of the actual and potential role that semi-public agencies and non-governmental organisations can play. Particular effort needs to be made to elicit community support in meeting special educational needs.

**Government's Role:** Government have a responsibility to monitor external funding to special needs education and work in cooperation with their international partners, to ensure that it meets national priorities and policies aimed at achieving education for all. Bilateral and multilateral aid agencies, on their part, should carefully consider national policies in respect of special needs education, in planning and implementing programmes in education and related fields.

## **B. School Factors:**

Developing inclusive schools that cater to a wide range of pupils in both urban and rural areas requires: the articulation of a clear and forceful policy on inclusion together with adequate financial provision - an effective public information effort to combat prejudice and create positive attitudes—an extensive programme of orientation, staff training and necessary support services. Changes in all the following aspects of schooling, as well as many others, are necessary to contribute to the success of inclusive schools: curriculum, buildings, school organisation, pedagogy, assessment and adequate trained staff.

Most of the required changes do not relate exclusively to the inclusion of children with special educational needs. They are part of a wider reform of education needed to improve its quality and relevance and to promote higher levels of learning. 'Education for All' underscores the need for a child-centered approach aimed at ensuring the successful schooling of all children. The adoption of more flexible, adaptive systems capable of taking into account of the different needs of children will contribute both to educational success and inclusion. The following guidelines focus on points to be considered in integrating children with special educational needs into inclusive schools.

**Curriculum Flexibility:** Curricula should be adapted to children's needs, not vice-versa. Schools should therefore provide curricular opportunities to suit children with different abilities and interests.

Children with special needs should receive additional instructional support in the context of the regular curriculum and not a different curriculum. The guiding principle should be to

provide all children with the same education, providing additional assistance and support to children requiring it.

Acquisition of knowledge is not only a matter of formal and theoretical instruction. The content of education should be geared to high standards and the needs of individuals with a view to enable them to participate fully in development. Teaching should be related to pupils' own experience and to practical concerns in order to motivate them better.

In order to follow the progress of each child, assessment procedures should be reviewed. Formative evaluation should be incorporated into the regular educational process in order to keep pupils and teachers informed of the learning mastery attained as well as to identify difficulties and assist pupils to overcome them. For children with special educational needs a continuum of support should be provided, ranging from extra help in regular classrooms to additional learning support programmes within the school and extending, where necessary, to the provision of assistance from specialist teachers and external support staff.

Appropriate and affordable technology should be used when necessary to enhance success in the school curriculum and to aid communication, mobility and learning. Technical aids can be offered in a more economical and effective way if they are provided from a central pool in each locality, where there is expertise in matching aids to individual needs and in ensuring maintenance.

Capability should be built up and research carried out at national and regional levels to develop appropriate support technology systems for special needs education. We should facilitate the free circulation of materials educational and cultural and equipment related to the needs of people with disabilities.

**School Management:** Local administrators and heads of schools and NGOs can play a major role in making schools more responsive to children with special educational needs if they are given necessary authority and adequate training to do so. They should be invited to develop more flexible management procedures, to redeploy instructional resources, to diversify learning options, to mobilise child-to-child help, to offer support to pupils experiencing difficulties and to develop close relations with parents and the community. Successful school management depends upon the active and creative involvement of teachers and staff, and effective cooperative team work to meet the needs of students.

Heads of schools have a special responsibility in promoting positive attitudes throughout the school community and in arranging for effective cooperation between class teachers and support staff. Appropriate arrangements for support and the exact role to be played by various partners in the educational process should be decided through consultation.

Each school should be a community collectively accountable for the success or failure of every student. The educational team, rather than the individual teacher, should share the responsibility for the education of special needs children. Parents and volunteers should be invited to take an active part in the work of the schools. Teachers, however, play a key role as the managers of the educational process, supporting children through the use of available resources both within and outside the classroom.

**Information and research:** The dissemination of information on good practices should help to improve teaching and learning. Information on relevant research findings would also be valuable. Pooling of experience and the development of documentation centres should be supported at national level, and access to sources of information.

Special needs education should be integrated into the research and development programmes of research institutions and curriculum development centres. Particular attention should be given in this area to action-research focussing on innovative teaching-learning strategies. Classroom teachers should participate actively in both the action and reflection involved in such inquiries. Pilot experiments and in-depth studies should also be launched to assist in decision-making and in guiding future action. These experiments and studies could be carried out on a cooperative basis by several countries.

### **C. Recruitment & Training of Educational Personnel:**

Appropriate preparation of all educational personnel stands out as a key factor in promoting progress towards inclusive schools. Furthermore, the importance of recruiting teachers with disabilities who can serve as role models for children with disabilities is increasingly recognised. The following actions could be taken.

**Programme Adaptation:** Pre-service training programmes should be designed and provided to all teachers - primary and secondary alike, positive orientation toward disability, thereby developing an understanding of what can be achieved in schools with locally available support services. The knowledge and skills required are mainly those of good teaching and include assessing special needs, adapting curriculum content, utilising assistive technology, individualising teaching procedures to suit a larger range of pupils. All teachers should be able to exercise their autonomy and apply their skills in adapting curricula and instruction to meet the needs of the pupils as well to collaborate with specialists and parents. The skills required to respond to special educational needs should be taken into account in assessing the competence of the curriculum and teacher certification.

As a matter of priority, written materials should be prepared and seminars organised for local administrators, supervisors, head teachers and senior teachers to develop their capacity to provide leadership in this area and to support and train less-experienced teaching staff.

**Teacher Training:** The major challenge lies in providing in-service training to all teachers, taking into account the varied and often difficult conditions under which they serve. In-service training should, wherever possible, be developed at school level through interaction with trainers and supported by distance education and self-instruction techniques.

Specialised training in special needs education leading to additional qualifications should normally be integrated with or preceded by training and experience as a regular teacher in order to ensure compatibility and mobility.

The training of special teacher needs to be reexamined and reconsidered with a view to enable them to work in different settings and play a key role in special educational needs programmes. A non-categorical approach encompassing all types of disabilities should be developed as a common core, prior to further specialisation in one or more disability-specific areas.

**Universities Role:** Universities have a major advisory role to play in the process of developing special needs education, especially as regards research, evaluation, preparation of teacher trainers, and designing training programmes and materials. Networking among universities and institutions of higher learning in developed and developing countries should be promoted. Linking research and training in this way is of great significance. It is also important to actively involve people with disabilities in research and training roles in order to ensure that their perspectives are taken into account.

**Role Models:** A recurrent problem with education systems, even those that provide excellent educational services for students with disabilities, is the lack of role models for such students. Special needs students require opportunities to interact with adults with disabilities who have achieved success so that they can pattern their own life-styles and aspirations on realistic expectations.

In addition, students with disabilities should be given training and provided with examples of disability empowerment and leadership so that they can assist in shaping the policies that will affect them later in life. Education systems should therefore seek to recruit qualified teachers and other educational personnel who have disabilities and should also seek to involve successful individuals with disabilities from within the region in the education of special needs children.

#### **D. External Support Services:**

Provision of support services is of paramount importance for the success of inclusive educational policies. In order to ensure that at all levels, external services are made available to children with special needs, educational authorities should consider the following:

- i. Support to ordinary schools could be provided by both teacher-education institutions and by the outreach staff of special schools. The latter should be used increasingly as resource centres for ordinary schools offering direct support to those children with

special educational needs. Both training institutions and special schools can provide access to specific devices and materials as well as training in instructional strategies that are not provided in regular classrooms.

- ii. External support by resource personnel from various agencies, departments and institutions, such as advisory teachers, educational psychologists, speech and occupational therapists etc., should be coordinated at the local level. School clusters have proved to be useful in strategies mobilising educational resources as well as community involvement. Clusters of schools could be assigned collective responsibility for meeting the special educational needs of pupils in their area and given scope for allocating resources as required. Such arrangements should involve non-educational services as well. Indeed, experience shows that education services would benefit significantly if greater efforts were made to ensure optimal use of all available expertise and resources.

## **E. Priority areas:**

Integration of children and young people with special educational needs would be more effective and successful if special consideration were given in educational development plans to the following target areas:

- i. Early childhood education to enhance the educability of all children
- ii. Girls' education
- iii. The transition from education to adult working life
- iv. Adult and continuing education

### **i. Early childhood education:**

The success of the inclusive school depends considerably on early identification, assessment and stimulation of the very young child with special educational needs. Early childhood care and education programmes for children aged up to six years ought to be developed and/or reoriented to promote physical, intellectual and social development and school readiness. These programmes have a major economic value for the individual, the family and the society in preventing the aggravation of disabling conditions. Programmes at this level should recognise the principle of inclusion and be developed in a comprehensive way by combining pre-school activities and early childhood health care. Many countries have adopted policies in favour of early childhood education, either by supporting the development of kindergartens and day nurseries or by organising family information and awareness activities in conjunction with community services (health, maternal and infant care), schools and local family or women associations.

ii. **Girls' education:**

Girls with disabilities are doubly disadvantaged. A special effort is required to provide training and education for girls with special educational needs. In addition to gaining access to school, girls with disabilities should have access to information and guidance as well as to models which could help them to make realistic choices and prepare them for their future role as adult women.

iii. **Preparation for adult life:**

Young people with special education needs should be helped to make an effective transition from school to adult working life. Schools should assist them to become economically active and provide them with the skills needed in everyday life, offering training in skills which respond to the demands and expectations of adult life. This calls for appropriate training strategies, including direct experience in real life situations outside school. Curricula for students with special educational needs in senior classes should include specific transitional programmes, support to enter higher education whenever possible and subsequent support to enter higher education whenever possible and subsequent vocational training preparing them to function as independent, members of their communities. These activities should be carried out with the active involvement of vocational guidance counsellors, placement offices, trade unions, local authorities, and the different services and agencies concerned.

iv. **Adult and continuing education:**

Persons with disabilities should be given special attention in designing and implementing adult and continuing education programmes. Persons with disabilities should be given priority in access to such programmes. Special courses should also be designed to suit the needs and conditions of different groups of adults with disabilities.

**F. Community Perspectives:**

The successful education of children with special educational needs is not the task of the Ministries of Education and the schools alone, it requires the cooperation of families, and the mobilisation of the support of the community, voluntary organisations and the public-at-large as well. Experience from countries or areas that have witnessed progress in equalising educational opportunities for children and youth with special educational needs suggests several useful lessons,

**Parent Partnership:** The education of children with special educational needs is a shared task of parents and professionals. A positive attitude on the part of parents favours school and social integration. Parents need support in order to assume the role of a parent of a child with special needs. The role of families and parents could be enhanced by the

provision of necessary information in simple and clear language. Addressing the information needs of and training in parenting skills is a particularly important task in cultural environments where there is little tradition of schooling. Both parents and teachers may need support and encouragement in learning to work together as equal partners.

Parents are important partners as regards the special educational needs of their child, and to the extent possible should be accorded the choice in the type of education they desire for their child.

A cooperative and supportive partnership among school principals, teachers and parents should be developed. Parents should be encouraged to participate in educational activities at home and at school (where they could observe effective techniques and learn how to organise extracurricular activities), and in the supervision and support of their children's learning as well.

Governments should take a lead in promoting parental partnership, through both evolving of policy and legislation concerning parental rights. The development of parents' associations should be promoted and their representatives involved in the design and implementation of programmes intended to enhance the education of their children. Organisations of people with disabilities should also be consulted concerning the design and implementation of programmes.

**Community Involvement:** Decentralisation and local-area-based planning favours greater involvement of communities in education and training of people with special educational needs. Local leaders should encourage community participation by giving support to representative associations and invite them to take part in decision-making. To this end, mobilising and monitoring mechanisms involving local civil administration, education, health and development authorities, community leaders and voluntary organisations should be developed.

Community involvement should be sought in order to supplement in school activities, provide help in doing homework and compensate for lack of family support. Mention should be made in this connection of the role of neighbourhood associations in making premises available, the role of family associations, youth clubs and movements, and the potential role of elderly people and other volunteers, including persons with disabilities, in both in-school and out-of-school programmes.

Whenever action for Community Participative Rehabilitation is initiated from outside, it is the community that must decide whether the programme will become part of the ongoing community development activities. Various partners in the community, including organisations of persons with disabilities and other non-governmental organisations, should be empowered to take the responsibility for the programme.

**Role of Voluntary Organisations:** As voluntary associations and national level non-governmental organisations have more freedom to act and respond more readily to expressed needs, they should be supported in developing new ideas and innovative delivery methods. They can play the roles of innovator and catalyst and extend the range of programmes available to the community.

Organisations of people with disabilities i.e., those in which they themselves have the decisive influence - should be invited to take an active part in identifying needs, expressing views on priorities, administering services, evaluating performance and advocating change.

**Public Awareness:** Policy-makers at all levels, including the school level, should regularly reaffirm their commitment to inclusion and promote positive attitudes among children, among teachers and among the public-at-large towards those with special educational needs.

Mass media can play a powerful role in promoting a positive attitude towards the integration of disabled persons in society, overcoming prejudice and misinformation, and infusing greater optimism and empathy about the capabilities of persons with disabilities. The media can also promote positive attitudes of employers towards hiring persons with disabilities. The media should be used to inform the public on new approaches in education, particularly as regards provision for special needs education in regular schools, by popularising examples of good practice and successful experiences.

## **G. Resource Requirements:**

The development of inclusive schools as the most effective means for achieving education for all must be recognised as a key national policy and accorded a privileged place on the nation's developmental agenda. It is only in this way that adequate resources can be obtained. Changes in policies and priorities cannot be effective unless adequate resource requirements are met.

Political commitment, at all levels, is needed to obtain additional resources and to redeploy existing ones. While communities must play a key role in developing inclusive schools, government encouragement and support is also essential in devising effective and affordable solutions.

The distribution of resources to schools should take a realistic account of the differences in expenditure required to provide appropriate education to all children, bearing in mind their needs and circumstances. It may be realistic to begin by supporting those schools that wish to promote inclusive education and to launch pilot project in some areas in order to gain the necessary expertise for expansion and progressive generalisation. In the generalisation of inclusive education, the level of support and expertise will have to be matched to the nature of the demand. Resources must also be allocated to support services for the training of mainstream teachers, for the provision of resource centres and for special education teachers or resource

teachers. Appropriate technical aids to ensure the successful operation of an integrated education system must also be provided. Integrated approaches should, therefore, be linked to the development of support services at central and intermediate levels.

Pooling the human, institutional, logistic, material and financial resources of various ministerial departments (Education, Health, Social Welfare, Labour, Youth etc.) territorial and local authorities, and other specialised institutions is an effective way to maximise their impact. Combining both an educational and a social approach to special needs education will require effective systematic and structured management enabling the various services to cooperate at both national and local levels.

### ***III. Guidelines for Action at the National and International Level:***

International cooperation among governmental and non-governmental, regional and interregional organisations can play a very important role in supporting the move towards inclusive schools. Based on past experience in this area, international organisations, intergovernmental and non-governmental as well as bilateral donor agencies, could consider joining forces in implementing the following strategic approaches.

#### **A. Nationally:**

**Assistance:** Technical assistance should be directed to strategic fields of intervention with a multiplier effect, especially in developing countries. One important task for international cooperation is to support the launching of pilot projects aimed at trying out new approaches and capacity building.

**Partnerships:** The organisation of regional partnerships among countries with similar approaches in special needs education could result in the planning of joint activities. Such activities should be designed to take advantage of economies of scale, to draw upon the experience of participating countries, and to further the development of the respective national capabilities.

**Focal Points:** A priority mission incumbent upon international organisations is to facilitate exchange of data, information and results of pilot programmes in special needs education between countries and regions. Collection of internationally comparable indicators of progress in inclusive education and employment should become a part of the worldwide database on education. Focal points might be established in sub-regional centres in order to facilitate information exchanges. Existing structures at the regional and international levels should be strengthened and their activities extended to such fields as policies, programming, training of personnel and evaluation.

**Size of Disability:** A high percentage of disability is the direct result of lack of information, poverty and low health standards. As the worldwide prevalence of disabilities is increasing,

particularly in the developing countries, there should be a joint international action in close collaboration with national efforts to prevent disability through education which, in turn, would reduce the incidence and prevalence of disabilities, thereby further reducing the demands on the limited financial and human resources of a country.

## **B. Internationally:**

**Assistance:** International assistance to special needs education derives from numerous sources. It is, therefore, essential to ensure coordination and compatibility among organisations of the United Nations system and other agencies lending assistance in this area.

**Cooperation:** International cooperation should support advanced training for educational managers and other specialists at the regional level and foster cooperation between university departments and training institutions in different countries for conducting comparative studies as well for the publication of reference documents and instructional materials.

**Regionwise:** International cooperation should assist in the development of regional and international associations of professionals concerned with special needs education and support in the dissemination of newsletters or journals as well holding of regional meetings and conferences.

International and regional meetings covering issues related to education should ensure that special educational needs are addressed as an integral part of the debate and not as a separate issue. As a concrete example, the issues of special needs education should be put on the agenda of regional ministerial conferences organised by UNESCO and other governmental bodies.

International technical cooperation and funding agencies involved in support and development of 'Education for All' initiatives should ensure that special needs education becomes an integral part of all developmental projects. International coordination should effectively support universal accessibility specifications in communication technology underpinning the emerging information infrastructure.

It is intended to guide member state and governmental and non-governmental organisations in implementing principles, policy and practice in special needs education.

# Tertiary Education & Transition to Workplace for Students with Disabilities – The Indian Experience

## **Introduction:**

Preparation through training and education with concurrent mobilisation of a support network is essential for persons with disabilities to transcend from one stage of life to another. At every transitional juncture, effective programming alone can enable them to cope with the challenges of change in themselves - physical, emotional and behavioural - and also the changes in expectations of them by others in different socio-cultural contexts. However, shaping their knowledge, skills and attitudes through a purposeful pedagogy during their transition through adolescence to adulthood has a profound bearing on their dignity and their quality of life as adults.

Many recent case studies have come to notice relating to Psycho-social status of young persons with disabilities which have implications for framing appropriate educational programmes. Universally, it has been acknowledged that education and training have to be adapted to provide outcomes that at least closely parallel the aspirations of young people with disabilities for community integration, meaningful career and a contributory social role.

Irrespective of the nationality, every young person with disability is entitled to a qualitative life with capabilities that present him/her positively. Breaking of barriers to their participation with dignity in the community, requires the involvement of many agencies, professionals, sectors and departments apart from families and the communities. The approach has to be two pronged.

- a. Promoting capabilities of youth with disabilities optimally through systematic and effective education and training.
- b. Preparing the community to utilise their capabilities through meaningful participation opportunities.

Though there is unanimity in recognising the need for reviewing and revising existing systems of education to achieve the goal of successful transition to real adulthood, a stereotyped approach cannot be adopted. Nations differ in the socio-economic, cultural and political scenario. Therefore a system of education that is viable and relevant to each country has to be evolved. However, it is essential for representatives of the nations to acquaint themselves with successful

models and to apply them to their own context if need be, with suitable modifications. Cost-effectiveness of many approaches in developing countries could be drawn as examples also by the advanced nations and the technology of the advanced countries could be translated to match the affordability and appropriateness for implementation in developing countries. An attempt is made here to narrate the Indian experience of enskillment and empowerment of young persons with disabilities to reach adulthood and to a work environment.

## **2. Tertiary Education and Transition of Youth with Disabilities, in India:**

### **a. The Traditional System:**

The traditional system of education emphasised a 'Career Development Approach' to education. The 'Gurukula' education that was accessible to the priestly class and the warriors and administrators, viewed the horizons of career to extend much beyond the concept of paid work or income-generation. It focused on preparing a pupil to evolve conscious efforts that were beneficial to himself and to others. The individualisation of the teaching-learning process targeted the shaping up of the pupils to assume their prospective primary social roles like student, priest, administrator, warrior and also other complementary roles which were vocational, familial and civic. The educational inputs encompassed academic, occupational and economic aspects of life, along with allied issues of adulthood like guardianship, marriage, friendship and parenthood. Students with disabilities were also churned out to be effective contributory members in their post-education phase of life.

In the case of tradesmen, artisans and peasants, the family's traditional work skills were passed on to the young children who got assimilated into the work force with passage of time. Young workers with disabilities are encountered even today in such settings in rural areas. However, the influence of Western systems of education has caused the extinction of the traditional approach to education to a considerable extent.

The futility of graduating from a system of education which prepares ill-equipped youth has been highlighted for over a century by great spiritual and national leaders like Swamy Vivekananda, Mahatma Gandhi, Rabindranath Tagore and Dr. S.Radhakrishnan. The need for 'Man Making Education' was reiterated by them. But, India's efforts, through nation-wide initiatives in facilitating easy transition to work and career development of young persons with disabilities are at the stage of infancy.

### **b. Barriers to Tertiary Education and Transition to work of youth with Disabilities in India:**

-- Services for people with disability are looked upon more as charity than as a matter of conferring their right to education. The importance of special education, the method of implementation and need for large scale access to such education is not popularly

felt, sought or provided at all levels. The persons themselves and their families resort to ways and means of acquiring 'cure and care' more than education, skill development, training and work. The practice is further reinforced by the sympathy and charity of the community and paucity of service-delivery schemes.

- The huge numbers of persons to be catered to and the large geographical area most of which is quite remote and unreached by any rehabilitation service is another deterrent to nation-wide services.
- Children of primary school age are not yet covered with general educational facilities. Efforts to include children with disabilities in the learning programmes for universalisation of primary education are being contemplated upon now. So access to education for all young persons will be achieved only after a reasonable span of time.
- Constraints of resources for evolving relevant educational provisions for youth with disabilities is another barrier. At the first instance, infrastructural facilities are minimal.

Even if centres for further education are available and access to education is achieved, there are not many trained teachers who can meet the special needs of the students.

- The curriculum is more attuned to scholastic achievement or technical skill development rather than facilitating survival and participation in the community or the world of work.
- Education of children with disabilities is mostly in special schools which are situated in urban and semi-urban areas. Tertiary education therefore gets confined to those students who have had access to information on the facilities and who can afford to relocate to the towns where tertiary education is offered in the same premises or in other mainstream centres.
- **Low Levels of Awareness:** Young persons themselves and their families are not generally aware of the career prospects through any specific system of education and very few centres are available for career-guidance and information on vocational training options and outcomes. Even employers and policy planners have limited awareness on employability or work potentialities of persons with disabilities.
- Prevalence of widespread unemployment and under-employment population explosion and the consequent competitive nature of available job opportunities coupled with negatively-charged societal attitudes and lack of stringency in implementing the reservation of job opportunities or filling up of quota of jobs, leave the trained youth with disabilities with unfulfilled aspirations to transcend to the world of work. There is no mandatory provision of reservation of jobs for persons with Mental Handicap.
- The scarcity of opportunities for internship or apprenticeship in real work situations often leads to an eternal trainee role in sheltered settings for some youth.

- Inter-ministerial and inter-agency coordination and involvement of the community, need to be strengthened. Presently efforts on these lines are being initiated. Outcomes are yet to be felt nationally.

**c. Factors that are favourable:**

1. In India, there is no provision of unemployment allowance/social security or any other security benefits to families of youth with disabilities. Therefore there are no apprehensions of losing benefits if young persons transcend to paid work. Though invariably some of them do not get minimum wages in the private sector, any amount of wage earned by a young person, adds to the financial status of the family. Therefore families in the low SES bracket do not dissuade young persons with disabilities from taking up jobs. However, members of affluent families do not opt for jobs that do not match their family status.
2. Automation of work is relatively limited in India. There are innumerable semiskilled and unskilled jobs that can be taken up by young people with disabilities if more awareness is created.
3. The enactment of the 'Persons with Disabilities (Equal opportunities, Protection of Rights & Full Participation) Act 1995, holds promises of more human resource development education and training facilities and employment opportunities for young persons with disabilities.
4. Many Government Organisations and NGOs have been involved in the recent past in establishing tertiary education programmes which also include functional literacy-numeracy, personal management, leisure skills training, vocational training and job placements. Work trades which were related to Occupational Therapy are being replaced by training in trades which produce marketable products in sheltered workshops/regular training centres. This is likely to improve the employability of the trained youth with disabilities.
5. The initial experiments on on-the-job training and supported integrated employment are yielding encouraging results. The cost-effectiveness and the promotion of dignity and improvement in quality of life of youth with disabilities through integrated work, have brought in more advocacy for transition through this approach.
6. Self-employment of young persons with disabilities has received an impetus in the recent past. Operation of telephone booths, running of petty shops or enterprises with family support and partial funding support from the Government, have given visibility to the entrepreneurial abilities of these young persons in the local communities.
7. Special employment exchanges and special employment cells have been established by the Ministry of Labour to support persons with disabilities in job-search and placement.

8. National Awards, for employees with disabilities, effective placement officers and successful employers of disabled persons have been instituted to recognise their contribution in the rehabilitation process.

### 3. Provisions for Tertiary Education & Transition to Work:

Further Education and Training Programmes for youth with disabilities have for a long time been shouldered by Voluntary Organisations and religious institutions or missionaries of charity. Their services were restricted to a limited catchment area within which they were functioning.

Disability received national attention and concern only during the UN's International Year of the Disabled Persons (IYDP - 1981). Service schemes with a nation-wide coverage were contemplated upon by the Government of India during the Decade of the Disabled that followed. However, efforts to evolve a National Policy frame work or guidelines to support the planning process of the nation did not emerge until the mid-point of the decade of the disabled. The National Education Policy (1986) recommended integrated education wherever possible for children with disabilities and the establishment of special schools for those who cannot be included in integrated educational settings. However, clear guidelines for further education and training of adults with disabilities were not available.

The report on National Policy for the Mentally Handicapped, evolved as a result of the initiative of THPI - a voluntary organisation - included the recommendation for continuum of educational support and training for meaningful work. It also recommended reservation of 1% of jobs for persons with Mental Handicap.

An overview of the existing provisions show that the education, training, transition and employment of young persons with disabilities require strengthening of the inter-ministerial and inter-agency collaboration. The services are offered by NGOs mostly and by the Government of India, through its different ministries. Some services are funded and monitored totally by the Ministry of Welfare, some jointly by the Ministry of Welfare and Ministry of Education, and others by Ministry of Welfare and Ministry of Labour, some exclusively by the Ministry of Education or Labour.

'Disability' and 'Education' are included as state subjects as per the Constitution of India. However, most of the State Governments have no clear policy framework for education of persons with disabilities. Most of the existing schemes are centrally-sponsored and are monitored with the help of State Governments.

Access to education in the Colleges and Universities is provided by reservation of seats by the Ministry of Education. Provision for residential homes, mobility and other aids and appliances to the students are funded by the Ministry of Welfare.

The Industrial Training Institutes (ITIs) monitored by the Central or State Board of Technical Education offers reservation of seats for different training programmes for engineering and non-engineering courses. The performance of youth is evaluated by the Directorate General of Employment and Training (DGET). Some Special ITI settings are monitored by the Ministry of Welfare (Eg: ITI for training, adult deaf persons). It is funded and monitored by the Ministry of Welfare but the accreditation is provided by the DGET (Ministry of Labour). The time-bound training course requires minimum secondary school level education for engineering programmes and eighth class level for non-engineering programmes.

The Special Vocational Training and Rehabilitation centres called Vocational Rehabilitation Centres (VRCs) are under the Ministry of Labour controlled by the DGET. There are 17 VRCs nationally. Apart from training given in specific trades, the VRCs also have a placement division which helps in job search and job placement of young persons with physical, sensory impairments — visual and hearing — and mild Mental Retardation. The training is based more on capability than on previous educational accomplishments. However, those with academic background relevant to specific job-training, gain access to the same. District Rehabilitation Centres (DRCs) established by the Ministry of Welfare were also involved in a similar service. However, the 41 Special Employment Cells attached to the DRCs have now been transferred to the Ministry of Labour.

The Ministry of Labour also supports job-seekers with disabilities by identifying jobs for them through enrolment in the 47 special employment exchanges. The 914 regular employment exchanges cater to employment needs of job-seekers with and without disabilities. It is reported that the 17 VRCs have employed 20,000 job seekers with disabilities. Around 50,000 job seekers have availed the Special Employment Exchanges for their job placement. The Ninth Five Year Plan period will witness the establishment of more VRCs and a network of 3 Rural Rehabilitation Centres for each VRC. Plans are envisaged by the Government for a linkage between Government and Voluntary Agencies involved in tertiary education and transition to work of youth with disabilities.

Though programmes and schemes with a nation-wide infrastructure are developing, there is a large concentration of services in the urban areas. Youth in rural India do not have access to information or the infrastructure. Even the urban programmes have limited intake of youth, eg: the special ITI for adults who are deaf the only one in the country, draws youth from different states. Only twelve candidates for each trade are selected from among the candidates who undertake an entrance test. Therefore the schemes reach out to a very small proportion of young persons with disabilities. Most of them are dependent on their families for their economic needs. Some of them support the families by sharing the household chores or work of other members contributing indirectly to the efficiency, productivity and economic status of families. Large number of young persons with severe disabling conditions resort to charity

or idle existence.

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, was enacted on the 31st December, 1995. The long-felt, need for a comprehensive legislation for persons with disabilities was realised by passing of the bill with unanimous approval to expedite it by representatives of all the political parties. The bill was passed without any discussion, considering its indispensability to streamline the nation's commitment through a mandatory provision. The Act provides for appropriate facilities for continuing education, training and employment of persons with disabilities. However, with regard to persons with Mental Handicap, the Act advocates their further education and vocational training, but does not provide any mandatory provisions of job reservations. The entire nation especially persons with disabilities and other service-providers are looking forward for an early implementation of the Act. Presently, the Government has set up core committees for framing guidelines for inter-agency and inter-ministerial collaboration for effective implementation of the comprehensive legislation.

There is hardly any national level training programme for teachers of universities and colleges, and instructors of technical training institutes, on special educational needs of youth with disabilities. Special training centres offer need-based training to their staff though there is no uniformity in the content. Short-term orientation programmes are offered by some voluntary agencies and a one year Diploma on Vocational Training of persons with Mental Handicap has been introduced by the National Institute for the Mentally Handicapped.

While service-delivery does exist for continuing education, so also transition support for persons with different categories of disabilities and for persons with varying levels of severity of disabling conditions within the same category, the number of organisations offering them and the nature of service offered vary considerably.

Heterogeneity exists not only in the special educational needs of the service-users but also in quality of educational inputs and the outcome measures.

#### **4. Post-School Education for Young Persons with Different Disabilities:**

##### **a. Physical Handicap:**

Integrated education of children with mild physical handicaps is a commonly encountered feature. As they leave high school, they pursue higher education opting for technical, professional and academic courses leading to graduation, post graduation, doctoral degrees etc. They also acquire jobs relevant to their educational achievements.

As long as education is available and accessible in a neighbourhood school, children with severe locomotor disadvantages also attend schools. Even today school-goers who crawl

or move on crude crutches or other mobility aids and artificial limbs are seen. When it comes to high school education and further education and training, the architectural barriers, long distances to commute and access constraints in public transport facilities inhibit them from pursuing training or education.

Efforts to evaluate the residual capabilities of young persons with locomotor handicaps and to adapt education and training to match their capabilities are being made by many voluntary organisations, National Institutes and Vocational Rehabilitation Centres.

Information technology and computerisation which are ideally suited for work-simplification and efficiency-enhancement, still remain beyond the affordability for national level application. Sporadic cases of utility of hi-technology are reported.

The pace at which preparation and distribution of mobility aids are developed, indicate the need to expedite efforts in this direction so that more and more young persons can avail the support of the specific aid to optimally utilise the available meagre provisions for post-school training or education.

Transition to work of persons with physical handicaps are increasingly visible in urban areas in India. Self-employment ventures are frequently encountered. India is yet to gear up for providing successful tertiary education to youth with motor disadvantages caused by neurological impairments in the regular mainstream centres. Special training and educational centres are promoting their further education and work training in sheltered settings.

#### **b. Visual Handicap:**

Special Education for persons with blindness was introduced in India in the late 19th century. Some prestigious residential schools for the blind persons have as their alumni, many competent officers, academicians and entrepreneurs. Many philanthropists and social workers have established "schools for the blind" in different parts of the country. Government-run free residential schools have also been functioning in many towns.

The plus curriculum followed in schools, teaches the use of braille and other tactile and multisensory learning modes to blind children. It also provides training in mobility and orientation, communication, motor skills, self care and personal management skills. Empowered by the concurrent inputs of the plus curriculum, many children gain access to the National Curriculum of general education with special education supports in special schools for blind persons.

The project IED (Integrated Education of the Disabled) also evolved models for integration of blind children in regular schools with itinerant teachers and resource room facilities. Large scale production of learning material in braille and audio cassettes and the involvement of many voluntary agencies in providing mobility training, scribes for examinations etc., have

considerably supported transition from Primary to Secondary School and Senior Secondary School Education. Relaxations in curriculum content, examination procedures and provision of free supply of learning materials to blind students, have promoted their entry into the realm of education in large numbers.

Many blind youth report difficulty in transcending from special schools to mainstream colleges where their special needs are not as effectively met as in a special school. Computerised braille printouts, talking books, other electronic devices are gradually entering the field to reduce the barriers to equal opportunities in higher education. Reservation of seats to those who meet entry eligibility to courses is also provided. Blind youth have acquired graduation and masters degree. Many of them hold high ranking jobs as a result of further education.

Job opportunities commensurate with the academic background however, are not available to all those who qualify from different courses.

As a facility to enable easy transition to work from school, the Vocational Rehabilitation Centres (VRCs) under the Ministry of Labour, offer training in many trades to blind persons. The placement division of the centre and also many Special Employment Exchanges are involved in job search, job placement and employment.

Though a mandatory provision of 1% of reservation of jobs does exist, the employment exchanges are not intimated of the availability of vacancies. It is disheartening to note that jobs reserved for different categories of disabilities – physical, visual and hearing – remain vacant in many Government Offices despite the availability of many persons all over the country to fill the posts.

Many youth with low vision and partial vision report late detection of their disability and the consequent loss of crucial years of education which are distinctly marked with a history of poor performance. Large prints, consisting of visual material, illumination, environmental modifications are being introduced for vision enhancement only in recent years.

A major barrier to transcend to work, is the emphasis on 'Disability Certificates'. A medical/professional certifies the level of disability alone. There is no supporting document which highlights the residual capabilities of the young person based on a job sampling, work apprenticeship/internship. Thus a prospective employer is not provided adequate / appropriate information on capabilities.

In India, there are many vocal musicians and instrumentalists who are blind but have pursued music as a tertiary education programme. The recent past has witnessed people with visual handicap in many unprecedented work settings and self employment. Training and community supports are being popularised through CPR programmes. However, it is a bitter truth, that the available facilities and programmes have reached only a small proportion of the population.

### **c. Hearing Handicap:**

Just as in the case of persons with blindness, for those with severe hearing impairment (still called deaf in India) special residential and day schools offer primary and secondary education. However, unlike people who are blind, those who have a severe hearing handicap cannot assimilate easily in the mainstream system of higher education after schooling. It is not infrequent to find many of them who have cleared the secondary school leaving examination successfully in special schools. Relaxations in curriculum content and examination procedures are major supports in enabling them to adopt the National Curriculum in such schools.

Though alternate communication system like lip reading, finger alphabets and sign language, give an expression mode, the absence of universal competence to use the sign language by other people in different contexts, restricts the participation and also easy transition of persons with hearing handicap communicating through sign language.

Colleges or public services do not generally have facilities for interpretation of sign language. The Vocational Training Centres and some special centres for training of adults who are deaf offer training in sheltered settings in some traditional trades.

Though 1% of job reservation is a mandatory provision, the jobs that require high levels of educational attainment are not accessible to most of the youth with severe hearing loss. Jobs of lower cadre are acquired by some of them with the help of special employment cells and exchanges. Many of them establish self-employment ventures with a low outlay of budget by availing loans.

Young persons with mild and moderate levels of hearing loss are often found to have dropped out from regular schools due to repeated failures. Late detection of hearing loss causes scholastic backwardness. School health camps being organised in the recent years enable an earlier detection of the disability. Audiometry facilities, ENT hospitals, Hearing-aid preparing centres are available in urban areas. Though National Institutes offer the hearing aids free of cost and some voluntary agencies at subsidised rates, the child or youth with hearing loss does not consistently use the hearing aids that are provided. Auditory training facilities for those who use hearing aids are also not nationally available.

Despite several constraints on further education and job accessibility, many persons with hearing loss are found to be well-integrated in the rural community. Many of them participate in family trades or run small-scale enterprises. They lead ordinary lives. Most of them are married and parent their children with the joint family support.

### **d. Mental Handicap:**

As a condition shrouded in many misconceptions and negative stereotypical connotations, Mental Retardation faces non-cognizance and apathy from the community. Availability and

access to special education even in special schools is very limited. The proportion of school age children (0-14 years) identified to have Mental Retardation is 3%. Only a handful of Voluntary Organisations offer education-cum-training facilities for post-school age persons as an extension of the special education facilities. The work-training pertains to traditional trades like candle-making, weaving, chalk-making etc. Efforts for job placements in the community through supported transitional training and job negotiations are offered by very few organisations. Invariably other organisations retain them in sheltered settings which under-utilise their potentialities.

A holistic multidisciplinary approach to work preparation with concurrent training in self care, recreational skills, clinical interventions for disadvantages, need-based training, guidance and counselling for sexuality, self-advocacy, community integration and guardianship are incorporated in the programmes offered by only very few organisations. Comprehensive and integrated approach with effective networking for empowerment of families, employers, co-workers, peer group, community members allied service-providers in the community and the Government is essential for meeting the special needs at the transition stage in the lives of young persons with Mental Handicap.

Unlike other disabilities, the negative attitudes of community members towards Mental Handicap compounds the challenges to be faced by persons with Mental Handicap in rural areas. It is not infrequent to find many of them confined to their homes and restricted from participating in any of the family or community activities. The stigma of disclosing their backwardness in accomplishing many skills, inhibits families from seeking even the available services.

There are no legal provisions to advocate for job placements and internship of persons with Mental Handicap. Job reservations, incentives for employers to encourage them to employ youth with mental handicap, practised in other countries are absent in India. Access to work in organised sectors like large industrial houses and large-scale service industries is difficult due to resistance from Trade Unions. Many of them do acquire recruitment as casual labourers.

Apprehensions of family members on possibilities of exploitation and also status-consciousness of parents, prolong the span of time between determination of employability and actual entry into paid work. Difficulty in travel to place of training or work is a barrier in urban areas. However, with training and guidance, many young men and women with Mental Handicap help their families in family trades and household chores and also perform many voluntary works in the community. Some of them do acquire paid jobs in the community.

Rural India is generally characterised by low priority for scholastic attainments. The geographical area and the topography are conducive for safe mobility in the villages. Therefore, persons with Mental Handicap who are visible in the community and are capable of simple work skills, receive a social validation of their work potential and gain access to available

work. Some of them also get married and beget children. The social structure being well-knit, rural rehabilitation teams which have sensitised rural community, have found improvement in quality of life of persons with Mental Handicap.

On the whole, India is in the process of identifying ways and means of empowering young persons with Mental Handicap to avail of the services for effective education and training for promoting transition of persons with Mental Handicap.

Provision of free bus passes for persons with Mental Handicap to travel along with escorts in some states had made commutation affordable. Families are now able to travel to and from the training centres and work places in urban areas.

## **5. Empowerment of Young Persons with Disabilities:**

### **a. Role of Education:**

Transition to work is not an overnight miracle especially in the case of persons with disabilities. It has been realised that preparation for the transition cannot be commenced after school-leaving. It has to be a phased graded learning programme which provides preparatory inputs right from early stages of primary or elementary education. The horizon of education which is highly restricted to the 3Rs must widen to encompass many issues like sexuality and gender-based special needs, leisure and recreation, utilisation of community and public facilities, self-advocacy skills, ethical and antidiscrimination aspects, awareness on available services, legal and social provisions for transition and protection of rights. Apart from skill development, education also has the responsibility of shaping up the self-concept and confidence of the youth with disabilities. Organising regular career guidance and counselling sessions are indispensable. Pre-Vocational Skills and Recreational Skills are to be included at an early age.

Tertiary education which bridges school-based learning and paid work must also change the current trend of filling-up gaps in the academic skills. It must assume the role of consolidating the capabilities of the students for generalisation of acquired skills for application in the community and non-school contexts. School-leaving stage is a time when an outward move from sheltered to ordinary settings must be facilitated. In the case of persons with Mental Handicap, many persons who have been in the community, accessing community-based opportunities, are moving towards sheltered settings owing to changing family systems and values, lack of supports for integration, and other rehabilitation supports.

Unsupported transition of youth with disabilities has provided unsatisfactory outcomes. Youth training facilities available to ordinary youth, need to be made accessible to disabled youth to a greater extent in the community. Appropriate special educational and training support has to be extended to them even after job acquisition.

The duration of time between school leaving and gainful employment or contributory social role is often determined more by extraneous factors like staffing pattern, experience and training of staff, and commitment of organisations and departments involved, than the preference and eligibility of the student. Crucial productive years and the willingness to learn and to achieve remain untapped and under-utilised due to inadequate educational or training facilities and methods. Tertiary education for young people with disability must establish linkages with all the prospective agencies which are to be involved in the transition. It must also be fully conversant with the post- education transition needs specific to a working situation to support job retention.

**b Role of Families:**

The joint family systems and close community contacts were favourable factors in supplementing school education for preparing students with disabilities for a meaningful adulthood. The emergence of nuclear families, urbanisation, pre-occupation of family members, technological advancements and non-availability of appropriate facilities have all collectively distanced the youth with disabilities from participation in the community, optimally. The out-dated training inputs coupled with reduced support from families make accessing, acquiring and retaining a placement in real job settings more difficult.

The lack of awareness among families on possibilities of cost-effective transitional approaches like work sampling, work experience, on-the-job-apprenticeship and employment, makes them shop for sheltered training centres which are very few. Unrestricted expectations of a student or under-expectations are also reported as family-related causes for delay in transition.

**c. Role of Teachers and Instructors:**

It is a universally established fact that teachers in both special schools and ordinary schools have very little knowledge or perception on difficulties encountered by school-leavers to transcend to work. Most of them are also unaware of the pre-requisite learning that has to be provided to the students. The primary or secondary school teacher-training programmes rarely include any aspects of tertiary educational needs of disabled students. The special school teachers often have knowledge on the special needs to participate in sheltered settings alone.

Vocational instructors in different special settings who have qualified from mainstream training centres which do not have any curriculum component on special needs of persons with disabilities, implement the individualised programmes through trial and error methods. In some centres, special teachers are upgraded to vocational training units. Though their strategies for training are systematic, they are not familiar with the skills expected of a student at community work settings. Very few short term - or diploma programmes are available for appropriate staff development.

Tertiary education requires close collaboration with a wider network of support services and personnel. The teachers / instructors must have the managerial, inter-personal and team-building abilities apart from good counselling skills to coordinate the inter-agency involvement. They must also have clear knowledge of the different career options and the strategies of meeting the special needs of students in each of them. A positive attitude to expedite the transition within reasonable time by mobilising appropriate supports is indispensable.

**d. Role of Service Providers:**

The vision of organisations that provide tertiary education, needs to be clear. Many organisations providing further education for persons with Mental handicap are vague in their intent as to whether they are training persons with disabilities for work or are they centres for storing away trained persons as eternal trainees. Many of them do not have adequate work load and the idle time of students is not utilised meaningfully for training in independent living skills or leisure skills. The work settings to which youth with severe disabilities transcend are sheltered workshops. The meagre wages earned out of occasional job orders do not match the possible wages that could have been earned by the same worker had he/she been working in the community work setting.

The sheltered settings cannot be wound up. However, they could be retained as assessment centres for exploring the capabilities and interests of students. Students with high functional abilities must transcend to the community as early as possible.

The training/teaching centres must be in close touch with placement and employment agencies. They can furnish details of the actual capabilities and special needs of the student.

**e. Role of Policies, Legislation and the Government:**

The National Education Policy (1986) recommended that wherever possible, children with disabilities must be integrated in regular schools. Those with severe disabling conditions must be provided with special schools. The review of the policy by Acharya Ramamurthy Commission emphasised the need for establishing special schools for children with Mental Retardation. The Project Integrated Education of the Disabled (PIED) jointly launched by the NCERT and the UNICEF in 1987, has made some breakthrough in integrating children with sensory and orthopaedic disabilities in regular schools. However, the coverage under the project is only a minuscule of a large number of children who are yet to be encompassed into the realm of education.

Therefore, the wide gap between policy and practice, an inherent barrier to service programmes in developing countries, has not deterred initiatives of families, voluntary organisations, advocacy groups, and people with disability themselves, to enable the youth with disabilities to enter the work force. Irrespective of not accessing any system of education or training

or any systematic rehabilitation supports and despite marginalisation in opportunities, many young persons have been successful in transcending to work. The process of transition has been time-consuming, cumbersome, challenging, and the practices are at times far from conferring the dignity or the equality in opportunities and services which they deserve as people contributing to national productivity.

The special needs of persons with Mental Handicap for transition, to date appears to be of low priority in the nation as a whole. As a significantly manifested learning problem, Mental Retardation, receives the least relaxations like modifications in the examination or evaluation of scholastic attainments, integrated education supports, intervention supports for other associated functional disadvantages etc. When entry to regular schools is restricted, special schools which are few in number are resorted to, by a few. A phenomenally large number of youth are reported to have had no access to education in their lives.

Work in the community acquired through family efforts or the supported employment services of NGOs have provided them the benefits of integration which education has denied them.

National Schemes and State Government Programmes envisage many benefits like free access to further education/ training or scholarships, residential facilities, books and learning material, travel concession etc., for youth with disabilities. Many schemes are implemented through support of NGOs. Collaboration between Government and NGOs and monitoring of implementation of Government schemes by the NGOs need to be strengthened. Incentives to providers of qualitative services and supports, stringent measures to implement policies and provisions, without violation of procedures are not effectively monitored.

Lack of awareness on service-delivery mechanisms and modes for disabled youth's transition among the bureaucratic system, often delays clearance of many proposals and projects. Policies and guidelines on procedures and formalities remain more on paper.

As a signatory to the UN Standard Rules (1993), India, has expressed its commitment to equalisation of opportunities by enactment of the 'Persons with Disabilities (Equalisation of Opportunities, Protection of Rights and Full Participation) Act 1995'. The implementation is yet to be initiated.

## **6. Women and Disability:**

The dual discrimination meted out to young ladies and women with disabilities marginalises them in acquiring even basic primary education. Their entry to tertiary education is relatively less in number compared to their male counterparts. Transition to paid work is rare. The nature of jobs for which training is offered are few. Many of them share household chores while a very few of them undertake self-employment with family support. Few of them avail facilities

like loans offered by the Government for establishing self-employment centres. Even sheltered training centres have more male trainees than female.

## **7. Steps to be taken in future:**

### **a. Awareness building:**

The post-school-age education of persons with disabilities requires more awareness-building on available options for continuing education and training. Career guidance, counselling and information dissemination centres, need to be established to cater to the information-needs of the youth and their families. Awareness on the existing infrastructure for transition to work and the procedure for availing the services must be created, so that, more young people will benefit from the services.

Employability of young persons with disabilities needs to be highlighted through different mass-media. Apart from the mandatory provisions, the social responsibility of employers both in Government and Non-Governmental sectors to provide them opportunities to work, must be emphasised.

Awareness-building among businessmen, industrialists and Government officers on the type of jobs that can be undertaken by persons with disabilities can improve the prevailing scenario, by enhancing the willingness of the employers to employ them and the means to identify appropriate job openings for persons with disabilities.

### **b. Large-scale Nation-wide Coverage:**

Launching of pilot projects, evaluation and small-scale replication will involve several decades for Nation-wide coverage. Alternatively, guidelines relevant to the needs and resources of different regions could be framed and schemes implemented with the involvement of State Governments, and decentralisation to the level of local authorities and village level leaders, which is proposed in the IX plan period (1998-2003). More autonomy in implementation of programmes and innovative schemes can be expected.

### **c. Human Resource Development:**

Right from policy planning to implementation level there is a need to train and orient the personnel on the special needs of young persons with disabilities for continuing education and training and for transition to work. More CPR workers and supervisors may be trained to enable the rural youth to avail the community resources for education, apprenticeship and employment.

### **d. Research and Documentation:**

Experiences of young persons in progressing through continuing education and work has to be studied and barriers encountered by them need to be removed.

Evaluation of existing services based on the quantitative aspects of coverage does not throw light on how far the services promote quality of life. Measures for quality of life of persons with disabilities like independence, integration, income-generation, improved relationships, meaningful leisure-time pursuits and control over matters relating to themselves, should be focussed upon. Research also needs to be focussed on comparative advantages of different systems (integrated or segregated) of education, training and employment.

In the cost-benefit analysis of tertiary education, the benefit of enhanced social value for people with disabilities may outweigh the material and monetary outlay on establishing effective services for the same. The disabled youth's contribution to national economy as purchaser of goods and services apart from being producer can also be studied.

The attitudinal changes arising out of tertiary education and work among disabled youth and among members of their family, employers and co-workers, needs to be focussed. Since persons with disabilities have limited experiences in life, some feasible instruments / checklists to determine their work aptitude / interest, can be evolved.

Research can play an important role in identifying cost-effective adaptations in jobs, work settings, working tools etc. It can also introduce high technology wherever possible to enable the young people to simplify complex tasks. Curriculum development for various culturally relevant work training and staff development, needs to be explored.

## **Conclusion:**

India acknowledges that young people with disabilities should be supported for effective continuum of education and training, in order to transcend to work. The efforts to bridge the gap between intention and implementation need to be expedited.

Despite several constraints, our dream to achieve better educational opportunities and more participation for people with disabilities in the mainstream of life is marching towards the day of its realisation. The pace of the same needs to closely parallel the aspirations of many young persons.

# Implementation of Persons with Disabilities Act - 1995

(Equal Opportunities, Protection of Rights and Full Participation)

## Introduction:

Education serves as an inevitable and essential link in the Rehabilitation continuum for persons with disabilities. Education is a process of graded development of knowledge, attitudes and skills in the pupils to prepare them for a meaningful, participatory and contributory role in adulthood. Special Education also has the same purpose though it may vary in the process of conferring the 'education' on pupils with special educational needs. Therefore it is imperative to contemplate on how effectively the two systems can be dovetailed at all levels to evolve an integrated approach for education of children with disability. When the nation is celebrating half a century of its independence and when the world is on the threshold of the 21st century, it is the basic responsibility of the country to implement the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 in its true spirit of eliminating discrimination in full participation opportunities and encroachment on Human Rights in matters relating to education of children with disabilities.

This paper gives a brief overview of the possibilities of meeting the clarion call of "Education for All" with due emphasis on adaptation in educational provisions for facilitation of access to education for children with disabilities. It also provides some recommendations for framing action plans and few schemes for implementation.

## 2. Overview:

Disability of any category does not necessarily result in homogeneity in special educational needs (SEN) of children identified in the same category. The etiology, the ecology and the ethology have their own influences on the nature of the severity. Special Educational needs and the special educational provisions are to be envisaged for appropriate education. Despite their heterogeneity, effective education should provide children with special educational needs, the strength to live in a rapidly changing society, through enjoyable and meaningful learning experiences, effective instructional strategies relevant, to their functional levels, restructuring of the environment to overcome architectural barriers healthy peer-group and societal attitudes, and modification in evaluation systems and conducive administrative and bureaucratic will

Education for all implies education of children with disabilities as well. It is high time we consolidate our experiences and research findings to eliminate denial of education on grounds of disabilities to children and minimise 'dropping out' or 'pushing out' of children already availing educational opportunities on the pretext of their failure to learn. The onus rests on us to provide appropriate learning facilities.

The cost effective approach of Inclusive Education strongly recommended by the Salamanca declaration still remains at an experimental level. The comprehensive infrastructure for education has to gear up to meet the special Educational needs of children with disability. While many children with mild and moderate disabilities can cope in the existing regular schools with support mechanisms, the children with severe disadvantages requiring specialised services can avail the special schools with intervention by specialists.

### **3. The School for All:**

Even today children with mild levels of disabilities especially mental retardation are transported long distances from their home even in urban areas to avail the Special School facilities as they do not get an admission in normal schools. It is high-time that schools - Government or Private - are equipped to accommodate children with disabilities in their vicinity and to provide meaningful education. While access to physical environments trained personnel to deal with multi-ability groups, resource persons, aids and appliances, curricular modifications, adaptations in examination procedures funding, research, family and community involvement and political will are issues which need to be addressed loudly to scaffold the process of inclusion, the possibility of availing an equal opportunity at par with the able-bodied peers, of being part of a natural environment cannot be denied to children with disabilities.

While providing a physical proximity with normal children is an initial step towards inclusion, inclusive education should cater to optimum access to the educational opportunities offered to the other children in the school.

#### **a. Other Educational Placement Options:**

If the severity of the disability and the intensity of the Special Educational Needs make inclusive education in a regular class room 'restrictive' to the development of a child, alternate placement options with scope for integration in nonacademic activities or social events needs to be provided through special units in regular schools, special schools, home-based training or care.

#### **b. Implementation of Disabilities Act 1995:**

Education plays an equally vital role in the developmental period of life of children with disabilities as in other children and any investment on qualitative education is bound to improve the quality of their participation in the society and their access to equal opportunities

in many other contexts in life. It is heartening that after four and half decades of formulation of the constitution of India, we now have a comprehensive legislation to defend the rights of people with disability, to promote equal opportunities and to provide full participation.

The provisions for education of children with disabilities cover major aspects, but they need an operationalisation to evolve active plans and to initiate schemes for implementation. Deliberations need to be focussed on some major issues.

#### **4. Identification and Assessment:**

Education of children with disabilities is child-centered. There is an imminent need for early identification of the disabling conditions and an assessment of their impact on the Special Educational Needs of the children. Apart from a multidisciplinary diagnostic assessment, a clear assessment of special educational needs has to be made. The assessment has to be backed up by a follow-up action and review.

##### *Schemes Recommended:*

- \* Enumeration of children with disabilities is essential to determine the framework of provisions to be incorporated for the education. National Institutes, Non-Governmental Organisations and other professional bodies competent to undertake surveys and detection camps may be supported through schemes of assistance, commensurate with the magnitude of the size of the population or challenges in accessing the target group.
- \* Establishment of Special Educational Assessment centres by specialists drawn from Government organisations, NGOs, Universities to advice on placement decisions. Schemes of assistance may be planned by evolving categories according to the catchment area covered or number of beneficiaries.

#### **5. Pre-School Education:**

Early childhood and Pre-School education are very crucial for the development of infants and children with disabilities. As a preparatory phase of life, the children with disabilities themselves and their parents are at very preliminary stages of coping with the impact of disabilities. Home-based training programmes and early childhood education must aim at guiding the family and empowering the child through early interventions and educational programmes. Since children with disabilities need more time and more practice in acquiring skills through stimulation of development and compensation for impaired functions, early education and importance of the pre-school programmes cannot be underestimated.

##### *Schemes Recommended:*

- \* Home-based training programmes, (through visiting teachers or parent training programmes for early childhood education for children with disabilities) organised by Government

organisations, NGO's or local Community Members may be brought under scheme of assistance.

- \* Pre-schools, Anganwadis and Balwadis offering free and competent education for children with disabilities may be funded for the programmes. Such early integration opportunities also enhance the possibilities of inclusion.

## 6. **Primary Education:**

We are making efforts towards make primary education a fundamental right of children, programmes to include children with disabilities need to be evolved.

Support Personnel like resource teachers, itinerant teachers, parents, volunteers, peer-tutors need to be mobilised. Different curricular options like regular education curriculum, identical curriculum through Special Educational approaches, parallel curriculum, lower grade level curriculum, functional academic curriculum, life management curriculum have to be identified.

Curriculum has to be subjected to modification, substitution, omission or compensation based on the S.E.N.s of the pupil. The objective-based curriculum transcends often to a process-based curriculum with flexibility and accommodation.

### ***Schemes Recommended:***

- \* Inclusive Education programmes for (School for all) pupils with multicategory of disabilities can be undertaken as demonstration projects and the program can be improved with evaluation and feedback of the project for replication. The initiatives of Government schools run by the Central (Kendriya Vidyalayas) and the State Governments, local authorities, NGO's and Private Schools may be supported by schemes of assistance based on the quality of education offered. A strict monitoring mechanism may be evolved to study the efficacy of the project. The project from its inception to its evaluation should be provided with professional and technical supports, appropriate aids and appliances, access to resource centers and trained human resource or inservice training of the participating personnel.
- \* Integrated education of children with a single category of disability in Primary Schools may also be considered for immediate nation wide implementation. Scheme of assistance commensurate with the strength of children with disabilities and their special needs may be extended.
- \* Special Schools for children with severe handicap may be established in areas where they are not available. In order to cater to the needs of children in remote areas, special schools as resource centres, day centres and residential learning centres may be started. Initiatives of Government and Voluntary Agencies may be financially assisted based

on the remoteness of the location and the quality of services delivered.

- \* Scheme of assistance for library facilities for children with disabilities and also for the teachers involved in teaching them may be provided in schools where children with disabilities are included.
- \* Support services like therapeutic intervention, transportation, health care etc., required for children with disabilities must be offered free.
- \* Access to all recreation facilities and leisure time pursuits available to other children of the same age must be offered to children with disabilities. Any special training support or adaptation in materials must be funded by the Government.
- \* Parents, volunteers and peers who can support the education of children with disabilities must be provided orientation and guidance on Special Education needs. Literature, guest lectures or demonstrations must be organised. Expenditure towards such training may be financially supported by the Government.
- \* All Special learning equipments, teaching aids or other compensatory aids and appliances may be provided free to the children with disabilities attending schools against a certificate of regularity of attendance by the school authorities or recommendation of district education officers, competent sources of supply may be identified and authorised in the proximity of residence of the children to provide the same.
- \* Incentives like awards for exemplary performance or stipends should be provided to children who do not drop out for five years from the Primary Education system and it may be increased for further transition period upto Secondary school.

## **7. Secondary School Education:**

Young persons with disabilities who transcend to secondary education must be supported to meet the challenges of a career-oriented education because most of them do not have access to the innumerable professional and technical courses available to normal learners, considering the fact that they require more practice and adaptations for skill acquisition, it is essential to utilise the crucial stage of their lives for meaningful pre-vocational skills and social survival skills.

While norms for adaptations in competencies and examination procedures prevail for the pupils with other disabilities, there is no relaxation in competencies or examination strategies that would enable children with mild Mental Retardation to qualify in board examinations based on projects or oral examination. The lack of accreditation by an examining authority to confer a certificate of acquired competency, leaves them with limited Post-School options. It is recommended that children with M.R. of Secondary School age in regular or Special Schools

may also be provided certificates based on reports of their acquisition by the Board of Secondary Education. Similar certificates may be issued for Higher Secondary Education also as a beginning towards equalisation of opportunities.

## **8. Training the Teacher:**

Education of children with disability is an interactive process where the teacher plays a crucial role not only as the dispenser of an individualised education programme but also as a coordinator of all support systems to meet the special needs of the pupils in totality. The teacher detects their educational needs, plans appropriate programmes for participation in the curriculum, designs appropriate methodologies and mobilises the necessary resources. Teacher competencies promote positive attitudes about disability.

A majority of children with mild and moderate handicap require general educators rather than specialists in inclusive settings. Resource Teachers with non-categorical multi-disability training can often meet the special needs of children in a "School for All" approach to integration. There is increasing evidence that exceptional students with mild or moderate disadvantages need little in the way of distinct instructional strategies. They may need more time, more practice or an individualised approach but not an explicitly distinct strategy from that used for other students.

For children with severe disabling conditions and multiple disabilities, specialised approaches and many special services need to be mobilised. Teacher preparation must consider the development of competencies to coordinate with multidisciplinary professionals and incorporation of therapeutic interventions in the schedule of the pupils. Special teachers for special school education also can serve as trainers, resource teachers and offer guidance to regular teachers and families.

### ***Schemes Recommended:***

- \* Pre-Service Teacher Preparation programmes like Diploma in Pre-School education, Balasevika Training Programmes, Secondary Grade Teacher Training, I.C.D.S., B.Ed. and M.Ed. Programmes must compulsorily include "Special Education" in the curriculum contents. Practicals and field placements must also include teaching of children with disability. Incorporation of disability-related inputs in existing programmes makes the teacher-preparation aspect cost-effective.
- \* The major challenge of providing in-service training, taking into account the varied and difficult conditions in which teachers serve, should be met by developing short-term local level workshops, with visiting trainers. Distance education support and preparation of self-instruction manuals have to be introduced. Initiatives for such programmes by NGOs government sector or competent field based professions, drawn from different

disciplines must be assisted through the scheme of assistance. Standardised curriculum must be evolved and the training evaluated for its efficacy.

- \* Regular refresher programmes on current development must be organised to enable trained teachers to update their knowledge and skills.
- \* Library assistance to Universities or training centres for reference material on special education must be provided.
- \* Preparation of educational audio-visual material for teacher preparation must be encouraged and assisted.

## **9. Coordination:**

Education of children of disabilities calls for mechanisms for coordination between concerned departments (health, welfare, education, labour, higher education, etc.) NGOs, National Institutes, Nodal agencies and organisations of and for people with disabilities and their families. The coordination will be offered at advisory and execution levels.

### ***Schemes Recommended:***

Formation of National, Zonal, Regional, District level Coordination Committees with representatives drawn from Government Departments, Non Governmental Organisations, families, etc. The committee will review the special education provisions and advice the Government on policy matters.

## **10. Research and Development:**

Disability and its impact on educational needs of children is very dynamic. Changing social challenges, and continued educational reforms apart from developing trends in other therapeutic interventions and introductions create a constant need for research and development in the field of education of children with disability.

### ***Schemes Recommended:***

- \* Research in the field of Special Education by regular school teachers, special school teachers must be funded to promote a scientific temperament in teachers to explore optimum educational possibilities for children with disabilities.
- \* Research methods be oriented to teachers to undertake systematic field-based studies and documentation of programmes. Short term workshops may be organised or funded.
- \* Efforts of Non-Governmental Organisations, Governmental Agencies, Professional Bodies for information dissemination of research-based data may be supported and assisted. Publications and organised information dissemination through Seminars, Conferences,

Symposia also require support and assistance. Development of National Data-Base, Directories, Compendia of Services etc., need to be initiated with regular updating.

## **11. The Role of the Family:**

The family, is an indispensable link in the education of children with disability. Gone are the days when they were considered just informants and dispensers of prescribed training targets at home. Today they are recognised as partners in the process of rehabilitation.

Parents have a right to information on assessment, placement decisions, educational programmes and provisions offered to their wards in schools. They must also be equipped with information on benefits and professional supports that are available to educate their son/daughter with disabilities. Motivation of parents influences the continuation of education of children with disabilities in regular schools as in special schools.

### ***Schemes Recommended:***

- \* Guidance and professional intervention supports must be provided to parents of infants and young children so as to promote the development of children.
- \* Preparation of self-instruction manuals on early childhood education of children with developmental delays and disability conditions for the parents. Initiatives on these lines may be funded.
- \* Information brochures on assessment centres, placement options, the role of parents, benefits in different educational provision programmes and procedures must be circulated for equipping parents with appropriate knowledge relating to various aspects of facilitating the education.

## **12. Preparation for Higher Education or Vocational Training:**

Another thrust area is the preparation of young persons with disabilities for higher education and vocational training. The extension of educational provisions beyond secondary school to a higher secondary level needs to be streamlined to equip the students with disabilities to achieve full participation and equal opportunities in higher education and vocation

Specific mention has to be made regarding the preparation of persons with Mental Retardation. The transition from training to real work needs to be facilitated through short-term training in training centres on job training in the community and transition to employment. Persons with severe disabling conditions must be prepared for meaningful living in the community with appropriate support systems.

***Schemes Recommended:***

- \* Accreditation of vocational training programmes and assessment and evaluation of vocational competence of persons with M.R.
- \* Self-instruction manuals on different vocational training options for parents and general instructors must be published.
- \* Career-guidance and counselling cells at community level or at least district level to orient young persons with disabilities on realistic options based on their potentialities needs to be established.

**Conclusion:**

Changes in policies and priorities cannot be effective unless the minimum resource requirements are met. Political commitment, at the National and Community level is required to obtain additional resources and to redeploy existing ones. While the community must play a key role in developing and sustaining service systems, governmental encouragement and support is essential to make them effective and affordable.

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*Rehabilitation and  
Rehabilitation Strategies*

# Role of NGOs in Rural Rehabilitation

## **Introduction:**

NGOs as we all know have played historical and significant role in the rehabilitation of Disabled persons both in developed and developing countries. NGOs have always been in the forefront in our country in responding to the challenging needs of rehabilitation of the Disabled persons in myriad ways. The contribution of NGOs in the field of Disability Prevention and Rehabilitation has been spectacular since a decade and a half. Their contributions in Social Rehabilitation and Community Level Interventions are unmatched by any Government action. Therefore, NGO action is not without loopholes. The fact remains, that they have established expertise and competence in some areas of rehabilitation especially in CPR Government while contemplating a joint action should be prepared to share certain responsibilities with NGOs so that NGOs are not confined to playing a second fiddle are reduced as passive recipients of government support.

## **Medical Health Services:**

There is enough evidence to show that to ensure the parents of children with mental retardation, there is a need for involvement of professionals from various fields. In this involvement, the role of medical profession is to provide medical services to treat those people with mental retardation, to identify the etiology of mental retardation and develop methods of treatment. The former has to do with the medical professionals' daily medical activities and is essentially the same as activities for people without mental retardation, while the latter is different. In this section, recent significant findings that could be, a foundation to promote daily medical activities for people with mental retardation on the basis of advances in the profession will be delineated, with supportive activities for them.

Auditory disabilities of people with mental retardation are often overlooked, especially with identification of the existence of a mild auditory disability which cannot be found solely on behavioural observation. It necessitates some professional examination. At present examination of the auditory brain stem response is possible at most professional agencies. If an examinee can be put to sleep by means of medication, this examination is much easier than Encephalography in which electrodes must be placed on the surface of the head. This examination may be helpful for people with possible auditory impairment. When an auditory impairment is identified as

a result of an examination, some intervention will be needed, depending on the degree of disability. Such intervention will lead to an improvement in the quality of their life.

Ret syndrome bears only among families starting in infancy, and results in the regression of the affected infants' mental and motor development in early childhood. This syndrome has recently been considered to be a most severe type of general developmental disability, that is an autistic developmental disability, in a broad sense, and the prognosis is not necessarily poor. Recently, an association of parents of children with this syndrome has been founded in United States so that increasing efforts can be made for the improvement of the social adjustment of children and adults with this syndrome.

Hyperactivity is frequently accompanied by a developmental disability; it raises challenges for treatment. This suggests that hyperactivity disorder with attention deficit that has hyperactivity as a major symptom and hyperactive disability may be closer to developmental disability. In the past, both hyperactivity disorder with attention deficit and hyperactive disability were not included in the concept of developmental disability that indicated mental retardation and general developmental disability. It is expected that the relationships among these symptoms will be made clear and some methods for treating hyperactive disorder with attention deficit will become applicable to the treatment of hyperactivity among individuals with developmental disabilities.

Various mental symptoms are apt to appear more among people with mental retardation compared to others who are not retarded. This is understandable if it is found that people with mental retardation are more likely to have brain dysfunctions than those without mental retardation, and that the former have difficulties in competence. Especially people with autistic behaviour characters have many more challenges than others with mental retardation. However, this point has not necessarily been detected due to undeveloped ability of expression among people with mental retardation. In addition to advances in biological studies recently, the psychology of people with mental retardation and general developmental disabilities is being understood from a more valid point of view, and supports and assistance for them are gradually being tried on the basis of this understanding.

Recently, in terms of chromosomal disorders, discovery of minimal anomalies have become possible, and the relation of autism to fragile syndrome has gained general attention in the field of developmental disabilities. In western countries, this relation is considered to be close, but professionals in Asia consider that it is not always so.

### **Government-Run CPR Programmes:**

It may also be noted that a study of the existing CPR programmes run by Government such as DRC have proved very clearly that though DRC has succeeded in delivering the package of services, it has failed to create an impact, as it did not succeed in involving the community networking. As a result, DRCs have become extended bureaucratic structures of

Government. These experiences must make us realise that while Governments can be effective in providing infrastructure and support, an effective CPR must and should preferably be run by NGOs.

**a. Demands of CPR:**

CPR is not a programme thrust on a community by an external body, through a TOP-DOWN approach. CPR has to be developed in consultation with the people, matching programmes with needs felt and expressed, where people are taken into confidence, their conscience aroused to contribute as responsible citizens. This is in other words a people-based approach and not a programme-based approach of Government. It calls for a very flexible, time-consuming, crisis-proof, frustration-proof persistent approach which NGOs are equipped for and is beyond the realm of Government personnel. This is not to say that all Government CPR programmes have failed, and all NGO-CPR programmes have succeeded. But to say, that in areas where NGOs have specialised in must be duly acknowledged and Government policy should encourage and sustain it and not to create parallel bureaucratic structures. An attempt is made to briefly share our experience with CPR.

**b. Areas for NGO Action:**

Following are a few areas where NGOs can take over definite and full responsibility in partnership with Government for the Rehabilitation of Disabled Persons in Rural Areas.

**c. An Experience with CPR:**

Thakur Hari Prasad Institute has been responding to the needs of the rural population through CPR and other interventions at the community level for more than a decade. Our 3 tier CPR programme at R.R. Dist. towards prevention, early detection and intervention of disabled children has succeeded in sensitising and involving of PHCs to prevention and early detection, local balwadis for integration, local schools for integrated education of the disabled children, local employers for vocational training and employment and so on. The entire programme was organised by interacting with the community and utilising its resources.

Apart from this, there is a great deal of rapport with ENT Hospital and NIHH for attending to problems of people with hearing handicaps, Eye Hospital for Visual defects, NIMS for the required surgery, guidance and prosthetic aids for Physical handicap, Niloufer Children's Hospital for paediatric problems, and so on. Preventive education was carried out through NIN for nutritional education, family planning centre for encouraging well-baby show, small families and so on.

These are the areas in which we have succeeded in networking with the local resources. This was made possible through personal visits, constant interaction, motivating the community to participate in rural camps, workshops, seminars and so on. Today if a case is referred to

any of these institutions by THPI, they are promptly attended to with concern. This relationship has been brought about not in a day or two. It is due to the committed and tireless effort of the THPI team over a period of time.

Other aspects of the programmes were, use of indigenous low cost and no cost training materials such as dried seeds, vegetables, clay, old tyres, kitchen utensils, tricycles, broken furniture and so on - as effective tools for early stimulation.

- \* Numerous awareness building modes were worked out. Some of them are 'Burrakatha, Street plays, folk songs, role plays, case demonstrations, exhibits, rural camps, local discussions and so on.
- \* Rural camps organised, apart from awareness creation succeeded in establishing rapport with the villages, elicited their participation for providing camp site, camp arrangements such as furniture, shamiyana, food, water; cooperation of PHC for immunisation, District Collector for providing transport support etc. These camps have made entry points towards initiation of rehabilitation services.

*What we liked to convey through CPR was ably achieved by:*

- \* Resource mobilisation
- \* Networking of local resources
- \* Eliciting community participation
- \* Required attitudinal change in the community
- \* Training of the existing functionaries to carry out rehabilitation services towards
- \* Awareness creation
- \* Identification of disabled persons
- \* Early intervention and integration
- \* Vocational training of adults
- \* Empowerment of the disabled persons and family members

However, it may be noted that when CPR strategies work effectively towards the rehabilitation of disabled persons, persons with M.R. needed certain special and continuous support. We could provide this as we have base centres in each village (balwadis and balwadi teachers specially trained by us for CPR programme). We need to have such resource centres in the community to attend to the special needs of M.R. Children, as we cannot expect over-

worked parents, busy with their survival needs to provide this care. So a comprehensive CPR model should have built-in provision for special care of persons with M.R.

### **Awareness Building:**

NGOs have been very successful and effective in this area through their target-based local media. Some of the materials on prevention are excellent for nation-wide replication. The concern for prevention has now extended to environmental factors too. The content differs from area to area. The target group, local conditions, cultural belief and practices determine the choice of media. But this is an area where NGOs have done excellent work through local media and otherwise. Some of the materials can be used for awareness building such as posters, video-films handouts and so on. But, they need support for quality and mass-scale production on a massive-scale to be a resource centre.

### **Human Resource Development (HRD):**

NGOs have experience, expertise and rich field laboratories - resources that are basic to the HRD in rehabilitation field. NGOs have identified certain community level functionaries who can carry out rehabilitation services nation-wide such as 'Balasevikas', Anganwadi workers and so on. With regard to the present plan, each district where the programme is to be implemented, the following personnel need to be trained.

- a. PHC Doctors
- b. Multi-purpose workers
- c. ANMs

In Tamil Nadu for example, training of anganwadi workers has been given to an NGO which is effectively carrying out the programmes in a phased manner. HRD must be entrusted to NGOs who have the required experience and expertise. Moreover, HRD in CPR cannot be just imparted by institution based professionals. It has to be imparted by experienced professionals who have felt the pulse of the rural population and endured with them. Such resources are available not in Books, Universities and Government run Institutions but with NGOs. Moreover CPR work needs certain amount of social passion, CONCERN AND EMPATHY as well as MOTIVATION which an NGO is equipped with. Therefore, for all known reasons training of human resource should be handed over to NGOs. This would also lead to strengthening the hands of NGOs in the partnership so that they can continue to be contributors.

### **Coordination for Rehabilitation Activities:**

However, committed the health infrastructure system is towards rehabilitation, we should not be unrealistic to expect them to monitor rehabilitation per se. Their tasks may be confined

to providing adequate pre-natal, peri-natal, post-natal care and care of children at risk. If the PHCs are to carry out these tasks effectively, the incidence of handicap can be reduced drastically. (New causes due to environmental factors such as air pollution due to industrialisation, modernisation of agriculture farming etc., need to be effectively covered under awareness building). But many other areas need to be looked into such as integration of disabled persons in mainstream programmes for education, vocational training, employment and so on. We need to work with various sectors to make this happen. Therefore there is a need for an external agency support to coordinate with these sectors in ensuring the effective and conscious implementation of the planned programmes to the targeted beneficiaries. This task cannot be done by the health sector personnel who are already burdened with their overwork. This role of coordination by an outside agency can be entrusted to an NGO who can coordinate CPR through existing health systems at District levels.

### **Piloting of Projects:**

NGOs with their innovative approaches and wide experience can be entrusted with the task of developing models of service-delivery systems of CPR for mass-scale application. This can be a collaborative effort of Government and NGOs. Rural Camps for awareness building integration through balwadis, employment generation through local trades, are some of the successfully tried out initiatives of NGOs. Similar piloting can be done with regard to CPR per se for rehabilitation of the Disabled persons through convergence of services such as ICDs and PHCs on a pilot basis, subject to periodic evaluation. Other areas where NGOs can play key roles are mobilisation of co-resources and advocating for human rights of the Disabled persons, and total rehabilitation of persons with Disability (this is a take over from where the health system ceases to care for them and seeing to their ultimate rehabilitation through remunerative job or work/employment and marriage.)

### **Rural Rehabilitation:**

In very simple terms it means, ensuring all possible rehabilitation support towards total rehabilitation of all disabled persons in the community by maximising:

- \* Community Participation
- \* Resource Mobilisation
- \* Mass Transfer of Technology
- \* Convergence of Services
- \* Empowerment of Disabled Persons and
- \* Family and Community



This means we need multi-sectorial collaboration for effective implementation of Rehabilitation Programmes in Rural areas.

### **The Rural Scenario:**

- \* Nearly 70% of India's population belongs to the rural areas.
- \* A large proportion of families live under the poverty line. Their life is characterised by poverty, illiteracy, ignorance, ill health and a constant struggle for survival.
- \* Children suffer from communicable diseases and malnutrition that are a potential threat to brain development, environmental deprivation, labour under hazardous conditions and no-schooling.
- \* Knowledge on disability and its prevention is totally lacking.
- \* Basic health care facilities are either not available and if available are not utilised by them due to lack of information.
- \* Rehabilitation services for Disabled persons are non-existent
- \* Prevalence of superstitious belief and unhealthy practices
- \* Disability is accepted as an "inevitable evil" and tolerated and neglected where struggle for survival is of paramount importance.

### **Existing Scenario of Disabled Persons:**

- \* Around 80% of the disabled persons reside in rural areas.
- \* Mobility problems often remain unsolved (with the disabled persons unable to leave the house).
- \* Persons with M.R. are perceived as Mentally ill or left to "deteriorate" and to vegetate
- \* Those with visual and hearing problems grope to live with great difficulty (some times through sign language and otherwise)
- \* Schooling of disabled persons is seldom considered due to economic constraints and nonacceptance.
- \* They receive no vocational training (as they are seen as people who can't work or contribute)
- \* Poor health care facilities continue to contribute to the causes of disability.
- \* Environmental causes due to the change in ecological system are likely to contribute to increase in incidence of disability.

## **Community Resources**

### **Peripheral:-**

- \* Govt. Functionaries (ICDs, PHC,)
- \* Volunteers
- \* Local and Political Leaders
- \* Local Religious Heads
- \* Faith Healers
- \* Community groups (Mahila Mandals, Youth Clubs....)
- \* Local Teachers

### **Referral:-**

- \* District Hospitals (for diagnosis & treatment)
- \* School Authorities (for integration)
- \* Social Service Organisation (to assist in the social/economic/personal problems of disabled)
- \* Labour and Employment officials (for placement in integrated formal vocational training and jobs.)
- \* Legal authorities (Settling human resource conflicts)

## **Role of NGO in Rural Rehabilitation:**

- \* Awareness Building through local media
- \* Human Resource Development through training
- \* Coordination of CPR activities at Dist. level
- \* Piloting of CPR Models - Innovative Approaches
- \* Advocacy for human rights

## **Requirements of NGO:**

- \* Financial support for production of materials
- \* Infrastructural support
- \* Availability of Standardised Training Models
- \* Technical Support for R & D

- \* Recognition of their contribution.

### **Awareness Building for Target Groups:**

- \* Peripheral Resource Persons,
- \* Referral Resource Personnel,
- \* Professionals

Workshops and Seminars, Newspaper Write-ups, Radio Programmes, Short-term Training Programmes, Audio-Visuals, Video Films, Slides/Posters/Slogans etc., Pamphlets/Reading materials etc., Organising fete/Runs etc.

#### **Local Media:**

Folk songs, Street plays, Puppet theatre, Role plays, Dramas, Drum beats (Dandora), Hari katha/Burra katha, Community meetings, word of mouth campaign, personal interactions. Quality of production depends on the creativity, innovativeness and identification of local needs and situations.

### **Concluding Remarks:**

In view of the proposed plan of launching rehabilitation programmes for disabled persons through the existing health infrastructure of the country, NGOs have certain specific roles to play and they are:

- \* Awareness Building (information-based rehabilitation)
- \* Human Resources Development
- \* Coordination of CPR Programmes at District Level
- \* Piloting of National CPR Programmes
- \* Advocacy of Social Rehabilitation of Disabled persons.

To carry out this role NGOs would require support in terms of infrastructure building, production of training kits and materials, and training costs. The Government needs to part with these roles which can be taken over by NGOs and offer the required support within a planned framework of partnership.

It is also required that the NGOs reorient their philosophy and system to become partners of the planned system, implementing projects and programmes that are within the framework of accepted policies and programmes. As on date, NGOs have setup their operations in a manner, without much macro-level planning and collaboration with Government. Some NGOs

# Developmental Rehabilitation for the Mentally Handicapped

## **Introduction:**

This paper deals with certain rehabilitation strategies that work and strategies that are IMPERATIVE in the rehabilitation of the mentally handicapped in a developing country like India which has the largest population of around 20 million mentally handicapped persons. In India, we have not been able to eradicate the basic problems unemployment, poverty and subhuman living conditions despite our impressive advance in science and technology. The disabled suffer more because they have not been given the important attention, they require. We have paucity of resources, trained personnel and finance. Nearly seventy per cent of the population live in rural areas, so do the handicapped population where services for handicapped are totally non-existent. The present paper shares a few successful attempts, that could be EFFECTIVELY REPLICATED in responding to certain key issues like:

- \* What could be done to ensure that the needs of the large number of people are met?
- \* What could be done to use the incredibly valuable resources of people with disabilities, their families and communities in meeting the overall challenges?
- \* What have we done to prove the indispensable role that can be played by COs and voluntary social action in supplementing the efforts of the Government.

## **Concept of Developmental Rehabilitation:**

Developmental Rehabilitation needs to be defined in a broader sense as our understanding of the concept can limit our thinking process and action programmes. 'Developmental Rehabilitation' can be defined as those comprehensive and integrated actions and programmes that cater to all the three levels of prevention viz., primary prevention that includes health promotion and specific protection; secondary prevention that relies on early diagnosis and treatment of the impending disabilities and tertiary prevention that includes all the rehabilitation measures towards ability development and placement in open community.

### **1. Primary Prevention:**

Prevention services do not confine themselves to one disability, rather it forms the base for all disability prevention, and this is what time and again we have been stressed that the health sector should address itself to providing the BASIC HEALTH facilities to the poor

and needy. We do not want to step into the health sector nor do we want to delink ourselves from them. It could be rightly stated that the NEGLECT of health sector adds to the BURDEN of the rehabilitation scenario. What we need is an integrated approach wherein the efforts of health sector could be supplemented by ACTIVE PUBLIC AWARENESS and EDUCATION where we can play a significant role and we are already doing it through our rural camps and other extension service programmes.

## **2. Secondary Prevention (Early Identification & Intervention):**

It has been proved beyond doubt that the EARLIER you identify and treat a disability the BETTER. The cost of launching rehabilitation services could also be CONSIDERABLY REDUCED. A few models that we have tried out effectively and with success are described below:

### **\* Developmental Rehabilitation for the Disabled:**

(Surya Jyothi - (Urban Based Programmes))

This is a project that deals with all types of disability in children of 0-5 years. This system bases itself on the unique features of early development in order to help children with inherent or early acquired defects (Physical and multiple handicaps) in such a way that they do not become handicapped.

The major aim of this therapeutic system is to stimulate and aid this compensatory process through various early intervention procedures. The major procedures are: (1) Early diagnosis (2) Early therapy, and (3) Early integration.

### **\* Early Diagnosis:**

*The following methods are used independently or in combination:*

- a) Routine medical checkup for the new borns
- b) Special diagnostic methods using "Munich Functional Development Diagnostic System".
- c) Neuro-Kinesiological Diagnosis, and
- d) Screening by parents

### **\* Early Therapy:**

On the basis of a multi-dimensional diagnosis, concrete programmes are prepared for each child individually, and the parents are guided and trained as co-therapists to carry out the programme, in such a way that the therapy can be integrated in the daily routine of the

child. Munich Functional development therapy and Neuro-kinesiological therapy have been extensively used. Montessori individual therapy is offered to children who require it.

\* **Early Social Integration:**

Handicapped children of 2.6 to 5 years are integrated with the normal children of the same age group on very scientific lines based on Montessori curative systems. This type of education considers the neuro-physiological elements of learning with emphasis on the use of sense organs. Currently handicapped children are being integrated with normal children the ratio being 1:3.

Though this system was practiced in an urban set-up it can very easily be REPLICATED in any rural set-up. It may be noted that no sophisticated equipment or techniques are required to provide this therapy. EVEN A POOR, ILLITERATE MOTHER can easily learn and practice the method in one sitting with the therapist. This is a major component in our CPR-model.

\* **Early Identification & Intervention-A Rural Experiment:**

This has been a 3 year project that has successfully tried out a scheme of early identification, intervention and integration of disabled children through a community based care system that has relied on the utilisation of EXISTING infrastructure, personnel and resources. The pre-schools named balwadis served as the base centre. The pre-school teachers, one from each village and ten trained parents served as the key grassroot level workers. The available local resources were made use of for therapeutic and training purposes. This project was carried out in ten villages consisting of a child population of 7068 drawn from 2940 families. Consultation services were provided by the parent body —THPI..

\* **Impact of the Project:**

In total 593 handicapped children of 0-16 were identified and the required services provided, of which 158 children were mentally handicapped. Around 30 per cent of children are being integrated through the existing educational systems.

We have found that it is possible to attain comprehensive integration of children through the existing 'balwadis'. A large number of children have benefited in terms of early identification and intervention, who would have never been helped otherwise and left neglected in these remote villages. The parents, grandparents and wherever possible siblings, were involved in the training of the handicapped children.

The model however has its limitations too when it comes to the rehabilitation of the severely handicapped children who need constant training and supervision through home-based programmes. The idea is to suggest that the family takes this up. But when one thinks of families where both the parents and elder members had to be out of home to earn

a living for more than 10 to 12 hours a day, it would then indicate the need to promote a care centre. Promotion of such care centres and community living centres through community participation will receive immediate attention. The project as such has shown its impact by spreading itself to other 30 neighbouring villages.

\* **Low-cost Teaching Aids:**

One remarkable achievement of this project is the preparation of Low Cost and No-cost Teaching aids utilizing the Local Raw Materials such as seeds, fruits, vegetables, leaves, sand, stone, clay etc. It may be commended that by doing so we are providing second class care to the disabled. We have waited too long to provide first class care to the disabled and if we still wait to provide so, for all the needy, even the minimum facility they would benefit from will never be a reality.

\* **Rural Camp:**

Rural camp which was rightly called an Enabling approach has been found to be a very effective technique in Awareness building and in the early identification of disability in a big way and intervention in a small way. What is important is not the camp as a tool but the Philosophy behind it in involving the people in this developmental work. Enormous amount of manpower and people's participation was generated right from awareness building campaigns, conduct of door to door survey, arrangements of the camp etc. This was of course backed by the trained manpower viz. 60 'Balasevikas', without incurring any extra input in terms of finance and manpower, but EFFORT, TRAINING and MOTIVATION.

### **3. Tertiary Prevention:**

No country, however, developed can escape the reality of tertiary prevention though of course we can minimize its burden. Over a period of time THPI has evolved a series of comprehensive programmes such as diagnostic services, special education, speech therapy, behaviour modification, occupational therapy vocational training etc., to meet the various needs towards the Ability Development of children with a mental handicap and in enabling them to lead as independent a life as possible. My purpose here is not to narrate and discuss them, but rather to highlight the need of the day viz., Vocational training, community based care systems, parents forum and manpower training and research.

\* **Vocational Training and Placement:**

To be gainfully employed in a job that suits their abilities and needs and be able to care for themselves if not for their family is the major milestone in the ability development of a mentally handicapped person and the success of a rehabilitation programme. From this perspective very little effort has been made and the rehabilitation workers have to face the major challenges of developing vocational training skills that are:

1. Simple and low-cost;
2. Competitive,
3. Income generating, and
4. Locally relevant.

On the other hand we have the mentally handicapped persons who have (1) Lower level of skills (2) Need for long period of training (3) To some extent a sheltered environment to work (4) Absence of a feasible model and (5) Lack of awareness regarding their abilities.

In the entire country at present — especially with its vast reservoir of normal unemployed persons — suitable patterns of vocational guidance, training and placement do not exist. In such a situation we know the vocational training of the mentally handicapped is very difficult if not seemingly impossible. Training in unskilled jobs like domestic work, kirana shop, home management, animal husbandry etc., and semi-skilled jobs like tailoring, carpentry, handicrafts, horticulture etc., may appear out-dated and out-moded but though not appealing, they remain the most appropriate skills for these persons.

At present 60 persons of age groups 16-33 are being trained in carpentry, book-binding, handicrafts, tailoring, consumer store, home economics, candle making and the newly introduced plant nursery. A few adults have been successfully placed in the open community as gardeners, tailors and the like. We are going to introduce horticulture, seri-culture and more of rural skills in our rural projects. In partnership with the parents, we see a promising future for the mentally handicapped.

\* **Manpower Training and Research:**

To respond to the vast population of 18 million and more, with limited trained personnel, finance and resources, we need to generate as much as much manpower as possible to carry out the various programmes and activities. We need to train parents, teachers, community leaders and so on. The needs of these groups vary, and so too the training programmes. We have organised many such need-based training programmes from time to time which need to be standardised.

In this endeavour sensitise the trained professionals and para-professionals too and it also has become a major sphere of our training.

Successful experiments need to be documented and shared for replication. This has to be methodically planned, implemented, analysed for wider application. Research has become an inbuilt component of all our programmes and activities, to meet this requirement.

\* **Community Participative Rehabilitation:**

The slogan "Go-Rural" needs no emphasis in the context of developing countries like India where more than 70 per cent of the population live in the rural areas. It is a country of villages and towns that overflow with rich culture, and resources both human and material. Our experiences with community-based programmes have proved overwhelmingly that it is possible to provide the essential care to a large majority of the affected population through trained non-professionals within the existing infrastructure of the country. It is with this major thrust in mind that we decided to launch a pilot project at Rajahmundry in Andhra Pradesh, knitting all our experiences and components of various levels of prevention, aiming at the maximum utilisation of the existing infrastructure.

If we are realistic, we will see that the evolving ideas and practices of CPR have the potential of being not only more affordable, but more important, of being more relevant to the lives and future of many handicapped people. With more experience we may well evolve what we should have had all along a People Based Rehabilitation.

\* **Parents' Forum for the Mentally Handicapped:**

This could be conceived as an endeavour to build-up a partnership with parents or to enlist parents participation in all Possible Ways in the rehabilitation of the mentally handicapped. They could play various roles as (1) co-therapists (2) as catalysts, (3) as Policy-makers, and or (4) as resource persons. These roles as effective co-therapists and as catalysts have been proved beyond doubt in all our programmes. We have also found them successful as resource persons in our vocational training pursuits. The various efforts made to enlist their participation such as SELF-HELP groups, workshops, seminars, and individual guidance have been well accepted. The mentally handicapped person's group is conspicuous by the absence of spokespersons it needs to have a pressure group to represent them, speak for them, demand and fight for them. For this the parents need to be organised — the small parents group need to be strengthened. With this in view, we are going for a district level and later state-level parent's body, through a federation of all the small groups. This forum I anticipate should merge with the National Forum for Welfare of the Mentally Handicapped and would create a people-based movement which is the ultimate aim of THPI. This is perhaps what we can offer to the Nation.

\* **Role of THPI at the National Level**

We are keenly aware that the efforts made by us are just a drop in the ocean. We cannot claim to train all the manpower the country needs and offer the services to all the handicapped children. But perhaps, we can do our work by giving a direction to other rehabilitation ventures, safeguard the interests of the mentally handicapped and those who are working

for them and be a pressure group — this is what we have achieved in organising the National Seminar for the formulation of the National Policy for the Mentally Handicapped and in submitting a policy document with regard to the same (we await its enactment).

**Conclusion:**

I would conclude by stating that the developing countries should address their rehabilitation endeavours to a threefold approach — of community-based delivery of services with major thrust on mass scale early diagnosis, early therapy and early integration, and to those who have missed out this stage of placement in an open community or in a sheltered environment through appropriate and adequate training in an environment that promotes maximum ability development, with the maximum participation of the parents. It should become a TRIANGULAR EFFORT OF PARENS, PROFESSIONALS (Govt. and NGOs), and COMMUNITY in order to bring out the desired results.

## FOOT NOTES

### 1. **Main Features of Early Development:**

- 1) Remarkable capacity of the brain in a new born child to withstand damage
- 2) Myelination and functional maturation of the nervous system which is not complete until at least 3 years of age
- 3) plasticity of the nervous system (which implies the ability of a nerve to take over the function of the other cell or cells without losing its function).

### 2. **Munich Functional Developmental Diagnostic Systems:**

It is a comprehensive test measuring the functional areas in the first three years of life using the criteria of crawling age, sitting age, walking age, grasping age, fine motor age, deception age, speech age, language comprehensive age, special age and independence age. This forms a basis for "Early functional developmental therapy".

### 3. **Neuro-Kinesiological Diagnostics:**

The Kinesiological diagnostics based on postural reactions according to Vojta is an excellent method for early detection of neuro-motor disorders. These reactions together with a battery of primitive reflexes can help us in determination of the neurological age in young infants and can detect an impending cerebral palsy even before the appearance of first symptoms.

### 4. **Munich Functional Developmental Therapy:**

Which is based on MFDD system utilises all possibilities of optical and acoustical stimulation and especially social interactions to this full potential.

### 5. **Neuro-Kinesiological Therapy:**

The Kinesiological therapy according to Vojta has proved to be very efficient in children with impending or manifest neuro-developmental disorders. It stimulates the central functions of the nervous system from the Periphery. Indications of this type of therapy include impending or fixed cerebral palsies, peripheral and deformities of the spine and feet. A mentally normal child with an impending cerebral palsy has a 95% chance of normal motor development. It is all the more successful if it is started before 4 months of age.

### 6. **Montessori Medical Pedagogy:**

Montessori Medical Pedagogy has proved to be very useful in social integration of retarded children. It is based on the most important elements of the internationally known Montessori Education. This type of education considers the neuro-physiological elements of learning with emphasis on the use of sense organs. It is an active way of learning which

induces the child to work with the auto didactic Montessori Material. The furtherance of the child with integrated education includes -

- Activities of practical life
- Stimulation of the senses and social development of the child.

**7. Bala Sevikas:**

Bala Sevikas are rural balwadi teacher - pre-school teacher who have undergone a eleven months course on pre-school education, child development, motor and child health, health and nutrition, and on handicap among children. A Bala Sevika Training programme is an ongoing training programme run by the State Councils of Child Welfare sponsored by Indian council for Child Welfare. At present 36 centres are being run, each centre turns out around 60 Bala Sevikas every year. The basic educational requirement to qualify for this job is SSLC/SSC.

They have 15 days of block field work during which time each bala sevika has to complete a household survey on the health status of the family members. An additional component of identification of disability has been added to this schedule. So also preventive education for disability has been given special thrust in their health camps and health education camps.

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# Empowering Adults with Mental Handicap Through Work/Employment

## **Introduction:**

This paper attempts to share a few viable strategies in empowering persons with Mental Handicap through enskillment in a developing country like India and which can be replicated in any developing nations. Both types of strategies viz. strategies that work in urban settings and strategies that work in rural settings are discussed. However a major thrust is given to the strategies that can be applied in the rural context where more than 70 per cent of the population resides - with poverty, illiteracy, ignorance as the predominant characteristics. The needs of persons with Mental Handicap is given the least or no priority and professional services are non-existent in most of these areas. Superstitious beliefs and practices prevail. Stereotype images that persons with M.H. are 'perpetual burdens' to society who cannot work or earn dominate. The result is that we are confronted with adults with M.H. who irrespective of their abilities were denied opportunities towards skill development and who were condemned to a dependent and/vegetative living, and for whom any work-skill training has to start from the BASIC level.

Therefore the strategies discussed with the major thrusts on making training programmes ACCESSIBLE, AFFORDABLE AND APPLICABLE need to be viewed in the context in which they have been/have to be operationalised. The second major dimension that threads the whole approach is the total development of persons with M.H., and not viewing them as objects to be trained only for productive work. The premise therefore is that enormous amount of 'human investment' of professional effort is required in order to convert the abilities of persons with M.H. into creative/productive work and to enable them to lead a wholesome and fulfilling life.

Moreover, Vocational Training is mostly conceived as providing recreational activity or something to 'keep M.R. adults engaged'. It was never offered as a preparation for work or employment which is their basic right. Vocational training for employment has its beginning since less than a decade or so in our country. Open employment for persons with M.H. was never even envisaged in a milieu that has to confront the 'unemployment' problem of many educated/trained young persons. The current venture therefore, remains a major break through in empowering adults with M.H. as we had to surmount various socio-economic blocks and age old cultural biases. This venture also remains an innovative one as there are no text book

answers for enskilling persons with M.H. in a developing nation like ours and we have to come out with strategies that are viable, cost-effective and can be replicated.

### **We begin our sharing with a few case experiences:**

We place before you the case of one Ms. Andallu an adult female 25 years old who was being used by her mother for begging. The mother was a casual labour occasionally and the rest of the time resorted to begging to make both ends meet. When we first identified Ms. Andallu as a female with less abilities, she was in torn clothes, shabby to look at and highly disturbed emotionally. Our initial plan was to introduce her to some meaningful work in a nearby agricultural unit initiated by us, as she used to accompany her mother in agricultural labour some times.

It took six months for Ms. Andallu take interest, and attend work regularly in the field. The team had to face the 'resistance' of the mother on many occasions as she felt that her family income was disturbed because her daughter's attention was diverted to agricultural work.

### **But today.....**

- Ms. Andalu invests her abilities on agricultural work;
- She earns around Rs.20/- to Rs.30/- per day;
- She looks neat and is conscious of her appearance
- Her tendency to wander has been reduced to a marked extent;
- She comes to the field on her own as against being coerced;
- She has a better self-image and more a valued role in society and
- She earns respect from her mother and others at home;

We present to you another case of Ms. Bharatamma a 35 year old mother with 3 children who was condemned by everyone and was leading a totally dependent life. Her abilities have been channelised to attend to small paid tasks at a nearby pottery unit.

- Today Ms. Bharatamma is a proud member of society;
- She takes part in the household chores along with others;
- She attends to her children leaving more time for her husband to attend to other works;
- She started taking interest in self-care;
- She learned to respect her husband, children and neighbours;

- Today she looks and smiles at people in contrast to the earlier behaviour when she used to bow her head or walk away;
- Even her neighbours feel happy about her;

Her husband remarks with tears "I cannot believe this is my wife-she is a different person now..."

The team found Mr. Srinivas aged 31 years from a poor family, locked in a small dark hut, crouched in a corner. His mother worked in a nearby toddy shop. Mr. Srinivas was always locked inside as he lost his way once and mother was worried that the same problem would reoccur. The locally available trade identified was pottery. Initially we had a lot of 'resistance' from the mother as they belonged to a caste for whom pottery was a 'taboo' - (as pottery is traditionally practiced by the people of one particular caste). Our purpose was not to force an occupation that was not acceptable to them, but to enable Mr.Srinivas to get into some nearby work situation which he would like. The rehabilitation team however did not want to hurt the sentiments of his mother and was trying for an alternate work situation. A couple of weeks later, inspired by another successful case in the area Mr. Srinivas's mother requested us for his placement in the pottery unit.

- Today we cannot believe that he is the same person who was found locked in his hut;
- He mingles well with his co-workers, is regular to his work, takes initiative to attend to other side jobs during his free time and has become an efficient assistant in the pottery unit and he demands a raise in his wages;
- His work life has transformed him into a different person, he breathes and enjoys a new life... as a contributory member of society;
- If this can happen to Ms. Andallu, Ms. Bharatamma and Mr. Srinivas....

**It can happen to any MH person at any time,  
by utilising their hidden abilities.**

**We only need to Facilitate the process.**

In Ability Development Programme, we focus our attention on a group of people who are just like anyone else, who may have less abilities, a group of people who can think, feel and have the same needs like anybody else for a 'status' and a decent life in society.

## **Empowerment of Persons with M.H.:**

### **We mean:**

- \* Promote appropriate and meaningful work attitude, behaviour and skill training.
- \* Enable them to become contributory members to society through numerous possible ways:
  - Home-based activities.
  - Cooperatives
  - Enclave or sheltered employment
  - Supported employment in Private & Public Sectors.
- \* Supported Employment at Community level - home based and local-based trades.
- \* Enable them to work, earn wages and contribute to his/her well being as well as those around.
- \* Promote inclusion of persons with Mental Handicap in the World of work and their empowerment through better quality of life.

These are more easily said than done. Empowerment of persons with M.H. is an extremely difficult task in a cultural context where their rights are not even acknowledged, let alone its denial. Hence empowerment of persons with M.H. needs to be interpreted in the context of our socio-economic background.

### **Existing Contextual Background:**

- \* There are around 20 million people with Mental Handicap.
- \* Only basic services provided, haphazard and shouldered by NGOs.
- \* Govt. initiatives excluded persons with a Mental Handicap, till recently.
- \* Available services are grossly inadequate.
- \* Rural areas remain neglected.
- \* Unemployment remains a chronic problem.
- \* More than 50% live below poverty line.
- \* Not dominated by work ethics, individualism and independence.

Therefore, empowerment of adults with Mental Handicap has to be translated taking cognisance of the local milieu and situations. The concept of 'eternal childhood' dominates our culture. We are also influenced by various work related 'taboos'. For example, in middle class or upper middle class family in India, they would prefer not to send their grown-up daughter for a training which will enable her to go out and work—they would resist it vehemently, but may well accept a training that will enhance her skills in household activities.

### **Existing Scenario about Persons with M.H.:**

- \* Persons with M.H. are reduced to a state of dependence
- \* Their weaknesses are the focus of attention.
- \* Their strengths are not recognised.
- \* Meagre opportunities for their training, income generation and employment.
- \* Domination of negative stereotypes and beliefs about mental handicap
- \* Vocational training is viewed traditionally more as a Recreational Activity (keep them occupy)
- \* Enskillment as a necessity for employment and empowerment has its beginning only since a decade.

### **We need to change this scenario:**

#### **We focus on:**

- \* Bringing in a new perspective on empowerment
- \* Create a culturally relevant viable training system.
- \* Based on person - centered, family and community centered approaches.
- \* Holistic approach to the Empowerment of persons with a handicap
- \* Redefining Professional Roles as facilitators.

By fresh perspectives we mean an unconventional way of looking at empowerment through work/employment. It is not absolutely necessary for a person to have a job outside his home and earn wages. If a person is functional and can contribute in any way to the best of his/her abilities towards his/her welfare as well as that of others, we would consider it empowerment. For example, if a young woman can work at home, kitchen and assist in the household maintenance and other activities we consider it as part of empowerment.

- \* An allied concern is the inclusion of persons with M.H. in the world of work and through that in the community.

\* **Holistic approach to empowerment:**

We conceive empowerment as the TOTAL DEVELOPMENT of persons with M.H., which means not only development of work skills but also the development of the person on the whole. This involves a multidisciplinary approach that ensures adequate attention to his/her special needs for speech and language development, development of behavioural skills, social skills, gross motor and fine motor activities, development of leisure time activities hobbies and so on. It is the TOTAL CARE that we aim at and not just their employment.

By person-centered approach, we mean, that persons with M.H. be given priority their interests, and abilities should be prioritised above other concerns. These would inevitably necessitate a re-organisation of the 'mind-set' and 'operational strategies' of professionals towards letting persons with M.H. work and explore the joy of being somebody'. This involves a humanistic approach and "human investment" towards enskillment and empowerment. Simultaneously, professionals have to be alert to the development of the twin aspects - total development of the person as well as his/her productivity.

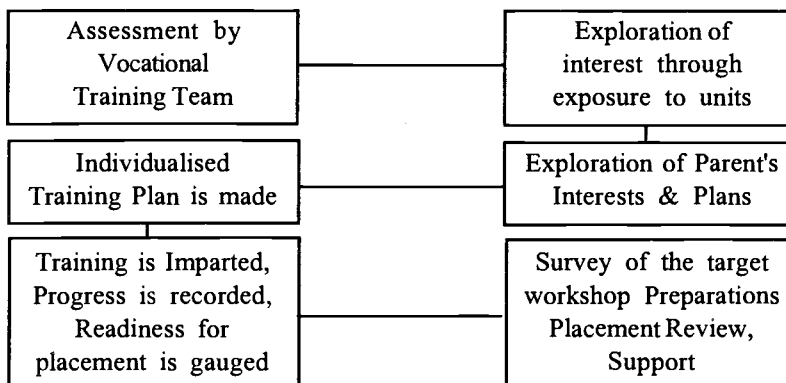
This perspective has been converted into action programmes through two approaches viz. Centre-Based Training & Placement, Community-Level Training & Placement. We had 3 groups of trainees:

1. Trainees who were in transition from Pre-Vocational Units.
2. Those who had entry to units with some prerequisite skills.
3. Beginners with no skills.

The two later groups are identified through Rural Camps which is an ongoing strategy towards awareness building and detection of people with Mental Handicap. In a programme of this sort we have more hurdles with the "beginners". A look at table No.1 and No.2 will reveal that we have to work with the differential needs of adults with Mental Handicap having differing capabilities and special needs. We had around 50% who have not received adequate professional support out of which around 20% are adult beginners, that is persons with M.H. who were never given any opportunity to develop and whose 'disabilities' were given a chance to dominate and submerge the 'abilities' leading them to a 'sub-human' existence in adulthood.

**Strategies Followed:**

Yes, there were no text book answers in empowering hundreds of such adult persons with M.H. We had to evolve our own strategies and work modules. The strategies followed both in rural and urban areas as shown in the following format:



Here, we need to look at one fact that it is not always possible to provide variety of exposures in a rural area as we need to weigh placement with regard to availability of local trades, willingness of the local employer to accommodate a person with Mental Handicap and so on. Under such circumstances we need to compromise on training a person in a locally available trade (simultaneously focusing on developing his/her interest). The two modules followed for training are:

TRAIN - PLACE - SUPPORT - Mostly in Urban Area

and

PLACE - TRAIN - SUPPORT - Mostly in Rural Area

We do not want to enter into any controversy on these models. Both have their own relevance. They need to be applied according to the relevance and demands of the situation. Let us have a look at our centre-based trades.

### **The Centre-based Training Trades of THPI:**

- \* Carpentry
- \* Horticulture (Nursery Maintenance, Kitchen garden, Potted Plants)
- \* Off-set press
- \* Letter Press
- \* Book Binding
- \* Xerox/Cyclostyling

- \* Tailoring
- \* Candle Making
- \* Bakery
- \* Home Management
- \* Consumer Store
- \* Commercial Cooking

We have to bear in mind that these are programmes evolved to develop work behaviour in trainees. It is not always the case that these trainees are placed in similar set-up outside, but the work behaviour developed facilitates its adaptation to other set-ups. Meanwhile support is also provided to incorporate additional skill requirements in the new set-up if any.

### **Community - Level Programmes:**

When we talk about interventions at community level we must look at it with reference to the far flung rural contexts of India. Hurdles come in the way of reaching services to these areas such as lack of proper roads, absence of communication channels, struggle for day-to-day needs and survival. Rehabilitation of adult persons is never thought of. Making inroads into these areas and breaking cultural barriers was never an easy task. But the THPI team has done it and it is POSSIBLE provided we believe in it.

At the community level we follow a three-tier model. Professional support is provided by the multidisciplinary team. Trained local supervisors and job coaches monitor the programmes at community level on a regular basis, with the support of the grass root level workers (Balwadi Teachers).

## Work Trades at Community Level

### SEMI RURAL

#### R.R.Dist

#### (Near Hyderabad)

- Agriculture
- Carpentry
- Welding
- Pottery
- White-washing
- Laundry Work.
- Poultry
- Garden Maintenance
- Small Scale Industry
- Salt Factory
- Text files
- Chocolate Factory
- Biscuit Factory
- Seed Factory
- Chalk factory.
- Tea shop
- Assisting in Clinic
- Others

### RURAL

#### Lalacheruvu,

#### (Near Rajahmundry)

- Farming
- Plant Nursery
- Carpentry
- Handlooms
- Cattle gazing
- Pottery
- Coir making
- Black smithing
- Laundry
- Household activities
- Brick-making
- Wood cutting  
(Timber Dept)
- Automobile Workshops
- Home-based Training

The message is that numerous opportunities are available in rural areas for the empowerment of persons with Mental Handicap. We only need to have the patience to reach out to them, identify local trades and place them with adequate support.

Another significant message is, that the community members will have the WILL, INTEREST and OPENNESS to accept persons with mental handicap for training and subsequent absorption into a suitable job. But, we need to realistically ponder over the need to provide some incentives to these local trainers in terms of raw materials, tools, repair work and so on, so that their interest and "out of the way investment" of time and energy is sustained. Otherwise there may be a risk of demotivation.

### Impact of the Programme :

The impact of the programme is myriad. They can be classified under specific impact on persons with a mental handicap and general impact on persons with a mental handicap.

## **Specific Impact :**

On the whole abilities of around 400 adults in the rural areas and 120 persons in the urban areas were channelised to productive work.

Many people who would have continued to waste their abilities have been put to use. For some it resulted in enhancement of existing skills which were put to limited use, for some others it resulted in a change of work leading to increased production. The non-tangible impact of this is the SMILE, the work status has brought on their faces. The feeling that they are SOMEBODY, the satisfaction that they too can WORK and CONTRIBUTE overrides all other impacts.

### **The other impacts are:**

- \* Better self-image
- \* Ability to contribute to the family income/work force
- \* Better acceptance by people around
- \* Improvement in quality of life
- \* Self-advocacy.

## **General Impact:**

- \* Empowerment of person with mental handicap
- \* Change in the perceptions of family members
- \* Increased Acceptance in the community
- \* Empowerment of community members
- \* Positive Response from Service Users
- \* Confidence in Professionals
- \* Family members are happy at the new prospects of their child. There is renewed hope and joy in them at the "never anticipated" changes. There is an increased acceptance of them and more valued roles.
- \* There is an amount of awareness generated in the community 'as seeing is believing'. This has led to change of negative and stereotyped attitude about persons with mental handicap. There is increased acceptance.
- \* Community participation was forthcoming in the identification of cases and referral by youth and leaders, in guiding parents for proper training, willingness of local employers

in providing employment and so on.

- \* The employer service users have developed better knowledge and positive attitude. An employer's meet resulted in overwhelming success with the resounding assurances of employers to employ persons with mental handicap.
- \* Parents participation was forthcoming in the decision making on placement for training, follow-up of training, identification of job in the community, job support, home-based employment etc.
- \* Awareness built up among the siblings through regular meets etc.

### **Future Perspectives:**

Our aim was not just to meet the target but to go beyond, which we did in fact. Our future efforts will be devoted to :

- \* partnership with employers (service user)
- \* intensify community networking
- \* greater awareness building.
- \* promote strategies for replication.
- \* Human Resource Development.
- \* Research & Documentation
- \* promoting self-advocacy.

### **Concluding Remarks:**

It is an extremely difficult task to measure the impact of a programme of this sort where certain parameters can be set such as member of persons employed, salaries drawn by them and so on. When this criterion certainly can become one of the parameters there are many other crucial issues to be considered:

1. Satisfaction and confidence of the family members and community members.
2. The learning gained by professionals for equipping themselves to face the challenge of empowering persons with M.H. through enskillment.
3. The "human development" in persons with handicap which is not susceptible to easy measurements (such as bringing a person with severe M.H. who had no previous exposure to any training programmes to a level of being able to care for himself with minimal assistance and be part of a workforce and a social unit.)

4. The INVESTMENT of time and effort by professionals in this "human development" of persons with M.H. and so on. Hence a proper evaluation of programmes of this sort needs to be SENSITIVE to all these aspects and take them into account.

On the basis of these considerations, we can confidently say that the strategy of 3As - ACCESS - AFFORDABLE - APPLICABLE for the empowerment of persons with M.H. is VIABLE and can be replicated. This programme is also cost-effective as it doesn't involve building-up of new infrastructures, but relies on BUILDING LINKAGES with existing resources for the enskillment and employment of millions of persons with M.H. in rural areas. This programme has relied on maximum utilisation of existing local trades as training venues and local employers as trainers. Further, the development of adults as PERSONS was and is our prime thrust and not merely work skill development.

Therefore we conclude with a word of caution, that our concept of empowerment will remain a growing and emerging concept. We conceived empowerment with the expertise, knowledge and experience we have acquired to date and we as professionals realise that we too are young at it. Our experiences are new at the vocational training and job placement of persons with a mental handicap. We have a lot to learn and a long way to go in understanding the process of empowerment of persons with a mental handicap and to translated into practice. We have to learn and realize with equal seriousness that it is feasible and viable.

Our concepts are bound to get transformed over a period of time as we go on incorporating newer meanings and a broader outlook - which goes beyond that of enabling persons with mental handicap, emerge economically productive, and in empowering them as citizens who experience life just like anyone else.

**Persons with Mental Handicap are not Handicapped Workers provided we understand their abilities and promote them. Let us not limit their abilities by our limited vision. Ways are numerous and Options are plenty and so are the difficulties.**

Let us work with a WILL & COMMITMENT so that **Tomorrow will find many persons with mental handicap** enjoying a better quality of life like anyone else, enhancing their "self-esteem" - through the empowerment process with strategies that are **Accessible, Affordable and Applicable.**

**Table - 1:**

**Status of Beneficiaries  
Identified Centre Based Programme**

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Total Trainees absorbed	-	146
On Training	-	110
Transitional Placements	-	17
On Job	-	11
Home Based	-	8

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**Table - 2:**

**Community Level Programmes**

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Total persons identified	-	403
On training	-	94
On full payment	-	69
Apprenticeship	-	81
Home-based	-	91
Newly Identified (Process of Induction)	-	68

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# THPI's role in the Rehabilitation of the Mentally Handicapped

## **Introduction:**

I will not be carrying out my responsibilities as a REPRESENTATIVE and propagator of VOLUNTARY SOCIAL ACTION MOVEMENT if I do not address the national and global challenges that we have to face in solving the problems of the mentally handicapped and their families and the community in which they live. Let me affirm right from the outset that disabled persons are only people who are "differently abled". If we do not recognise this fact and that the end result of all our efforts is to achieve equal opportunities and full community involvement by all members of our society, some of whom are people with disabilities. We have not even begun to accept our real responsibilities as politicians, experts, individuals, directors, professionals, workers, or whatever category we belong to. As we are gathered here, we have a responsibility to share ideas and knowledge and to communicate with one another during this time we have set aside and on our return to our homes to do the same thing and provide a clear-cut direction and perspective to rehabilitation plans.

*My paper, is an attempt to respond to certain key issues like...*

- \* What could be done to ensure that the needs of the large number of disabled people are met.
- \* What we have done and what could be done to use the valuable resources of people with disabilities, their families and communities in meeting the overall challenges.
- \* What could be done to develop partnership with Governments and its many sectors to assist in developing policies and services to meet the needs of the people we work for, when carrying out their responsibilities to all the people of the country they govern.
- \* What could be done to prove the indispensable role that is played by NGOs and voluntary social actions in supplementing the efforts of the Government.

In answering these issues, we have to spend time and effort and I have discussed the programmes that require priority and special attention. Mere lip service will not help, we will have to commit ourselves to seek solutions to the major concerns of the disabled, otherwise we will denigrate our own efforts.

## **Contextual Background:**

This paper essentially discusses the major programmes and plans of THPI in the context of developing countries. India is a developing country with a population exceeding 700 million, which makes it the second most populous country in the world. Eighty per cent of the country's population lives in the rural. Agriculture and allied occupations provide a livelihood to most of these. Majority of the people are illiterate and nearly half of them live below the poverty line. Literacy is high among men but among women it is around 19 per cent only. Forty per cent of the population are children below 0-14 years. Childhood mortality rate is 154 per thousand as per the recent figures (UNICEF, 1986) the number of children enrolled in school is 107:76 (male/Female) per thousand which speaks of the plight of young disadvantaged children in our country. Facilities for health, safe drinking water, schooling and means for making a decent living are scarce. The rehabilitation programmes for the mentally handicapped have to be viewed in this contextual background.

As is well known, a nation-wide estimate of the magnitude of the problem is not available, however the data from the available studies indicates a prevalence rate of 2 to 3 per cent, the number of mentally retarded in our country has been estimated to be nearly 18 to 20 million people. It has also been estimated that 75 per cent of the mentally retarded population are only mildly retarded, and the 20 per cent moderately retarded and 5 per cent beyond any hope and who need custodial care which means around 95 per cent mentally retarded children can be helped to function independently and around 75 per cent can be helped to function nearer to normal level with necessary help. These glaring figures indicate the population of retarded to be helped with training facilities viz., day care, training centres, vocational training centres, sheltered workshops, integrated schooling and residential care facilities.

We are also well aware of the fact that the services available to confront and combat this problem is of tremendous magnitude, services are grossly disproportionate in terms of personnel and resources. To date there are 150 known institutions in the country and their services can hardly cater to about 1 per cent of the retarded population. Then the fact also remains that the prevalence of mental retardation is high in the rural area when compared to the urban area, whereas the services available are primarily concentrated in the urban areas. The problem of mental retardation in the rural area is almost completely ignored.

Advanced knowledge in science and technology has made the care, treatment, rehabilitation and prevention of mental retardation possible. But the hurdle lies in the economic constraints of our country to reach the 18 to 20 million population of mentally retarded with this specialised care. The cost of launching sophisticated programmes is astronomical even for developed countries. There is also the problem of logistics: we have to wait for centuries before we have enough specialised personnel, say, 1,80,000 trained special teachers, to deal with the fringes of the problem. Moreover the trained personnel continue to be absorbed by the cities.

It is in this context that low cost programmes aimed at the large majority of the mentally retarded are considered realistic and pragmatic. This approach anticipates the involvement of non-professionals who would carry out the programme with minimum training, maximum manpower development and utilisation of available infrastructure.

### **Role of THPI:**

Thakur Hari Prasad Institute as a responsible voluntary body has been addressing itself to two major challenges: One annihilation of the sufferings of the Mentally Handicapped and their families and two, contribution to the rehabilitation field of mentally handicapped in terms of methods, techniques and models of care, keeping in view the needs and constraints of a developing country like ours. We have tried to respond in our own humble way with the technical acumen available with us during the last 20 years have been successful in many ways and perhaps, unsuccessful in certain ways. We may not have been very systematic and professional in our programmes but our goal throughout has been and is to attain professional perfection, and our attempts are sincere, and we are confident that with the present onward movement and the commitment of our working team of dedicated workers the attainment of our goals is not beyond reach. An attempt is made here to briefly discuss the various rehabilitation services and programmes of our Institute in the context of its relevance and scope in a developing county like ours. An attempt is made to schematise the various programmes and activities of the institute.

Essentially THPI rests on 3 major pillars. 1) Institutional and Non-Institutional activities, (2) National Policy (3) Action Research. A attempt is made to discuss the major programmes and activities.

### **Early Detection and Intervention:**

We have tried to implement this programme at institutional and non-institutional levels. At the Institutional level we run the research and development project "Surya Jyothi" in collaboration with the German experts. The main focus of this project is on early detection, early intervention and early social integration of infants and children afflicted with or threatened by mental, physical or multiple handicaps, on the model of the work done in Munich — identification through Kinesiological / Postural reactions and Therapy through Neuro-muscular stimulation using specific exercises.

Subsequent integration is done through Montessori environment. This project has been going on for the last three years and the results are quite encouraging. The total number of children helped by this programme is around 500. Parents of handicapped children are immensely happy and gratified with the improvement in their children. The project has aroused keen interest in professionals working in this field in India.

The basic premise of the therapy is that the brain nerves controlling the various neuromuscular functions of the body can be manipulated or stimulated for normal functioning if it can be done within the first five years of the child and the results are more promising if the disability is detected as early as the first three months.

It is well known that in a country like India where the facilities for rehabilitation of the disabled are scarce and not given due attention, we felt that it is our duty to spread this message of early detection and intervention. The cost of rehabilitation once the disability has crossed the critical period.

For the same reason we felt that it is our commitment to the nation to spread this movement as quickly and as widely as possible. With this in view two training courses one in Developmental Therapy for three months from Physio Occupational therapists hailing from different states and another one for 21 paediatricians was conducted. We plan to conduct many such training programmes in future too. Negotiations are also under way with the University of Health Sciences in Andhra Pradesh, to get this Developmental Rehabilitation incorporated in their Medical curriculum.

The second major project on Early Detection named "Anveshana", Early Detection and Integration was carried out in the neighbouring rural areas. This project was carried out in collaboration with UNICEF. The basic aim of this project is prevention, early detection and management of disability among 0-5, children within the existing infrastructure of the community. This project was also carried out successfully during the last three years in ten villages consisting of a total child population of 7086. Around 800 children were identified with various disabilities and among these nearly fifty per cent belonged to the 0-5 age group. These children were helped through ten trained balwadi teachers and ten trained mothers, (who served at the grass root level) with the periodical guidance, consultation and (sometimes direct service which was followed up by the grass root level workers) by the Clinical experts of THPI. Very simple methods of care and management were taught to them - which were locally relevant and affordable. It has been proved beyond doubt that prevention and early management of childhood disability is not only possible but could be carried out with increasing efficiency with minimum technical inputs and maximum utilisation of existing manpower and material resources. The rehabilitation of disabled children can be effectively carried out through homebound package programmes. With the confidence and experience gained from this project, the programme has already been extend to other thirteen villages, it is difficult to measure the impact of a project, especially where programmes are preventive and educational. However it can be evaluated in terms of:

- 1) The number of cases for which services, and training programmes were provided and necessary follow-up action taken.

- 2) Change in family attitudes and practices that are harmful or impeding the progress.
- 3) The level of awareness of the nature, needs and services for the disabled.
- 4) The amount of community participation generated.
- 5) The self-reliance of the project.

### **Special Education Programme:**

With regards to the Special Education of the Mentally Handicapped we follow the standard methods of setting individualised education plan (IEPs) and evaluating it over a period of time, on the basis of which future goals are set. Needless to say that team work is followed in its strictest sense in the assessment planning and evaluation of children. One significant aspect of our Special Education programme is the preparation of teaching aids out of low cost and locally available materials. Teaching aids are prepared out of waste materials such as cool drink bottles lids, seeds, egg shells, waste papers, pencil cuttings, newspaper and magazine cuttings and other such materials etc., Natural environmental materials are also used to teach the children various concepts of daily living. It is striking to note that a daughter of a vegetable vendor was taught the basic concept of colour, shape, small, numbers etc., with the help of vegetables only. She was also taught the alphabets with the help of vegetable seeds which she was a familiar with and which were easily available in her surroundings. With this approach even her mother did not find any difficulty in continuing the training at home. This principle is followed in the preparation of assessment kits and various therapeutic equipment.

The idea behind this is to simplify the education materials used so that the training of the mentally handicapped is possible and feasible to any one who wishes to do it. This would also make the training of the handicapped accessible to all sections alike rich, poor, rural or urban. We intend to develop a resource centre for the same, so that these techniques and methods could be shared with others.

We have also learned that education need not be imparted in concrete buildings but can be effectively carried out in huts with thatched roofs which can be adopted in any setting.

### **Integrated Education:**

While striving for excellence in the field of Special Education we are also very keenly aware and sensitive to the global challenge for integration, mainstreaming and normalisation. We may be questioned — why excellence at the risk of segregation? We have tried to answer this question in our own way. The methods of integration may vary from full integration into normal class room, to partial with the class room for special services, to special units functioning as parts of regular schools with integrated services, to special schools for all

handicapped children.

The challenge of integration is to transfer the best elements of special education to the ordinary school so that both are enhanced and so that the children benefit both socially and educationally. Countries that have little or no educational facilities for children with mental handicap have a number of possibilities open to them — but what is required is the will and determination to train and launch these programmes. Stray efforts have been made here and there in our country and most of the efforts have met with failure. The lesson learned is that the failure is not due to faulty models, but due to the lack of clarity of vision, commitment and perseverance by those who implemented it.

We plan to adapt the existing special facilities to the requirements of promoting the integration of the handicapped children with the normal children in other words using special schools as resource centres. We have tried to establish a network of links with regular schools. It implies that planned and regular links were developed between the special school and neighbourhood regular schools. For example, teachers from two schools work together to ensure that children from the special schools spend increasing periods of time in regular schools. Similarly there could be a system of planned mutual exchanges between the staff of special schools and regular schools. We are still young at it and we hope that this system will work out well to the advantages of the handicapped child, normal child, society and the community in general.

The global challenge we face more than the system of integration is not HOW to integrate but WHEN AND WHOM to integrate. We know that as the severity of disability increases the possibilities of functional integration becomes thinner and thinner. But the challenge remains at the “WHEN” level. The EARLIER the integration takes place the better — the most critical period being the first five years of the child — so the question of segregation and later integration does not arise at all. We have tried to integrate handicapped young children with the normal children through Montessori method in the urban sector and balwadis in the rural setting. The results are quite encouraging — so much so that a handicapped child is hard to identify by a stranger. This experiment calls for longitudinal studies on the basis of which scientific inferences can be made.

### **Community Participative Rehabilitation Centre (CPRC):**

We are well aware that the existing services do not answer the needs of the mentally handicapped in the rural areas that constitutes 70 per cent of the problem. The need for training, manpower development and devising local methods of training and integration is immense. Overwhelming evidence shows that CPRC is the only answer to this problem, though we do not have much experience specifically with the mentally handicapped. Very little knowledge and technical acumen is available regarding such programmes carried out in our country. But

we are convinced that it has to be done and we have to make a beginning somewhere. We have decided to start our first CPRC at Rajahmundry. Our plan is to develop a model rural centre along the lines of the THPI urban model. A classification of the type of services offered, the methods and strategy employed to suit the local needs, situations and affordability. For example, in the CPRC rural oriented skills such as farming, gardening, poultry, dairy grazing, weaving etc., will be taken up. This programme anticipates the involvement of non-professionals who would carry out the programme with minimum training. The major tasks of the CPRCs will be:

- 1) Setting up of a model centre
- 2) Training of the required manpower
- 3) Service delivery system
- 4) Evaluation and Replication.

### **Scope of the Project:**

The main objective of the project as envisaged is to evolve a comprehensive and integrated community approach to the rehabilitation of the mentally retarded children in our country and at the same time the delivery system should be appropriately oriented to reach the rural population at a minimum cost with dependence on as few as specialists as possible. In this approach the average time spent by the specialists in dealing directly with a few mentally retarded children can be diverted to the training of ancillary professionals and other workers who in turn could train and manage many more retarded children in the community with necessary guidance. Thus the efforts and time of our professionals could be stretched to the optimum use.

Our initial target is to cover a population of one lakh each in three districts through our model centres, which is nearly one fourth of the target population in the designated areas viz. Eluru, Tirupathi and Rajahmundry which have a total population of 11,07,327. These centres will become the model centres to extend the Community Participative Rehabilitation throughout Andhra Pradesh, to the mentally retarded. This is possible since these centres represent the three regions of Andhra Pradesh namely, Coastal Andhra, Telangana and Rayalaseema.

Given the prevalence rate of 3 to 4 per cent prevalence of mental retardation in our population, we can expect around 3500 mentally retarded children in each of the target areas. An estimated 38,756 retarded children are to be reached in the designated areas that the project aims to reach with the rehabilitation services. Through this model we expect to bring down the cost for the care of the mentally retarded considerably to the minimum possible extent in terms of manpower, material resources and financial implications, with the major thrust on

utilisation of available local resources, manpower and expertise. This project if found successful in the rehabilitation of the mentally retarded on a cost-effective basis as envisaged through trained "Balasevikas", could be recommended as a model for the community care of mentally retarded throughout the country.

### **Vocational Rehabilitation for the Mentally Handicapped:**

One other major challenge that we face is in the vocational rehabilitation of the mentally handicapped. Having a job or being gainfully employed fulfills an important human need as it instills confidence in oneself and confirms one's ability to care for oneself if not one's family. This need is particularly strong among disabled persons. In developed countries it is relatively easy to help the disabled person achieve this sense of independence and social usefulness. In developing countries, however, and particularly in rural and backward areas of such countries, where resources are scarce and professional help and specialised rehabilitation centres non-existent, the situation is much more difficult if not seemingly impossible.

India has the largest number of disabled persons. We, therefore, have to see how best this section of India's population can be rehabilitated. Despite our impressive advance in science and technology, disabled suffer more because science and technology have not been harnessed to make them mobile and productive. It is in this context the need to demystify the rehabilitation process is called for.

With this in view, we have started vocational training in **(1) Carpentry, (2) Tailoring (3) Crafts (4) Candle-making (5) Canning (6) Book binding and (7) Home management.**

Our aim is to make these persons self dependent.

Once the children master a particular activity they are given independent tasks. They are also given remuneration for their completed tasks. We are glad to note that some of our children have opened accounts in "Kiddies Bank" and have started saving the remuneration they get. We plan to introduce rural oriented skills like gardening, farming, poultry-keeping dairy farm management etc.

In addition we are providing training for students to work/help in hotels, to attend to telephone calls, run errands, to assist in kirana-shops, workshops etc., around 60 students ranging in age from 16 to 32 are being trained in this unit. We strive not just to train fifty or sixty children and be content with that. Our aim is to evolve a system of vocational training and placement on the basis of following criteria:

- 1) Simple and low-cost methods
- 2) Skills that are in demand in the open market
- 3) Skills that give tangential and economic reward.

#### 4) Availability of raw materials.

In order to help us out with the vocationalisation of mentally handicapped a council has been formed with the members from the faculty of THPI, parents of the mentally handicapped and a few prospective employers. We feel that it is a significant step in the direction of evolving a suitable module for the training of children in our setting.

One major task ahead is to identify the jobs that are relevant to our programme. In our programme

agricultural farm work will provide a useful outlet. Viewed in the prospective of industrialised countries, the idea of placing mentally retarded individuals to work in unskilled jobs in hotels and farms or any domestic services may look outdated and outmoded. However in an Indian context this type of employment is in line with the needs of the society.

### **Role of Industry in the Income-Generation:**

Another major role we have to play is to be a pressure group in seeking cooperation from industries. Both public and private industries can play a significant role in assisting the disabled in all forms of employment for income generation. In addition to providing jobs for disabled in their own industries, the industries can provide enclave employment where groups of disabled persons work as separate units under special supervision. They can help in numerous other ways such as providing simple home-bound work, help in the supply of raw materials to the disabled engaged in self-employment, marketing the products prepared by them and so on. The Government can also consider subsidies and special incentives to those employers who could place a certain number of handicapped persons, and adapt their technology and working environment to suit the requirements of the handicapped. The success of any vocational training programme is eventually reflected in the total number of handicapped persons placed in gainful employment. In the entire country at present — especially with its vast reservoir of normal unemployed persons — suitable patterns of vocational guidance, training and placement do not exist. At least for the purpose of eradicating the sufferings of some of the families who feel this absence most, these centers have to be developed.

### **National policy for the Mentally Handicapped:**

In the Indian context, strictly speaking, there is no law that exists for the welfare and protection of the mentally retarded citizens. The Indian Lunacy Act of 1912 makes a mention of the mentally retarded, but clubs them together with the mentally ill. The Indian Lunacy act has not undergone any changes from the time of its enactment. The law therefore is non-utilitarian and archaic. A new law is definitely called for. This has to be carefully planned because it is not enough if one institutionalises certain concepts by way of a law, for real social change, reform and advancement, it is the internalisation of concepts that is more important.

The law has to be one that takes into consideration social exigencies as well as the contemporary Indian situation as it exists.

One of the outcomes of the advancement in the field of medicine is the accompanying longevity in people which includes mentally retarded individuals. The mentally retarded tend to live a full span of their life, and one of the problems that is faced by many of the parents, is the provision to care for their mentally retarded wards after their demise. This problem becomes all the more acute because of the social change that is occurring in India due to industrialisation as well as urbanisation and the resultant loosening in the family system that existed. The joint family system had its own defects, yet provided a social cover for the weaker or the handicapped members in the family. In the modern context this role, which was previously taken by the family, is to be institutionalised and eminent persons have advocated a Guardianship plan for the mentally retarded. This is the main idea which involves the saving of certain amount of money over a fairly long period of time by the parents during their lifetime to look after their handicapped wards after their demise. The funds generated are handed over to a lawfully established Trust. The Govt. of India is already contemplating a National Trust for Welfare of the Mentally Handicapped in deference to the recommendation of the All India Seminar conducted by THPI, so that they take upon themselves the responsibility of looking after the retarded person during the entire life span of the retarded citizen through one of the institutions run by it. This is an essential need that is felt by many of the parents and would go a long way in ameliorating the anxieties of many of them.

Moreover, the mentally retarded individuals present a very wide range of problems which differ both in their nature and complexity. As such, different types of services - medical, educational, social welfare and employment - are required by them.

The planning and development of a programme and its coordination is a major administrative problem. This is so because in the Indian setting different ministries - Health, Education, Social Welfare and Labour- are concerned with the area. All these being "State subjects", the issue becomes more complicated as each state can evolve its own policies and programmes. This can bring about extreme differences in the services provided by different states. A vital step, therefore, is to evolve a national plan for the welfare of the mentally retarded persons.

THPI took the responsibility of evolving a national plan for the mentally handicapped in our country and with this purpose a national seminar was organised in February 1987 in which representatives from the concerned Ministries, Central Government, State Governments, Professionals, Voluntary Organisations parents participated and reached a consensus regarding the various aspects that should go into the policy paper. The policy paper covers all the aspects of mentally handicapped under the three major heads: (1) Prevention and Health (2) Education and Vocational Training and (3) Social Security.

This policy-document was released by our Prime Minister on Jan. 14th 1988 and was presented to all the concerned functionaries including the Planning Commission. An inter-ministerial committee has been constituted to work out the details of the policy, and a separate committee on Legislation to work out the details of the formulation of a National Trust for the Mentally Handicapped. It is indeed a spectacular accomplishment of voluntary social action that has happened for the first time in the country. We hopefully feel that the happiness is on the menu of the mentally handicapped too.

Since there is a total vacuum that no nodal agency at the national level is functioning as a representative body to plead for the cause of the mentally retarded, the seminar made a recommendation to form a National Forum for Welfare of the Mentally Handicapped. The THPI took initiative as a Chief promoter by taking upon itself the responsibility by constituting the NATIONAL FORUM FOR WELFARE OF THE MENTALLY HANDICAPPED, which will play a vital role by becoming a bridge between NGOs working in the field of the Mentally Handicapped and the Government. The National Forum formed has received affiliation status by the ILSMH.

### **Parents Movement:**

It is an indisputable fact that a great potential for the rehabilitation and subsequent normalisation lies in the family and community. These units should be the base for any therapeutic programme. The very disability is germinated from the family and community and no programme can ever be as effective as that which involves the family and community.

We need to tap this imminent force. But how do we do it? We need to develop general awareness among parents and families that human disability can be cured, prevented or arrested from further progression. Once a disability has occurred it must be detected early, its nature and extent must be assessed and given early intervention and stimulation so that further handicap can be totally averted. Once disabled, the individuals should be examined and given training that suits their potential, capacities and needs and enables them to develop their skills so that they can become self-reliant. To make these things possible it is imperative that deliberate efforts be made to involve the parents and family members in a planned and systematic manner. This programme also envisages the need for parental training.

Essentially, the parent training programmes aim to take parents as partners in care. They also transfer special skills of care to the parents. Follow-up periods of few weeks to few months, has shown that these programmes are effective as parents can take care of their handicapped children. This approach not only allows for the ideal utilisations of centralised facilities but also equip the available persons with appropriate skills for care of the mentally handicapped.

The self-help group movement is an expression of the potential for helping each other among families with mentally handicapped persons. This movement allows for services to develop within the homes and in all communities without excessive professional inputs.

This parent group which will initially be based in the twin cities will expand itself to the nearby districts and in the long run to the whole of Andhra Pradesh State. This body should be able to assume independent character over a period of three years and take up various programmes aimed at prevention and rehabilitation of the disabled. To start with we have two active parent groups in the institute — one a self-help group and another parent's group for the vocationalisation of the Mentally Handicapped. This group will form the base.

### **Research Programmes:**

Research is an integral factor and plays a crucial role in the development and formation of any programme on scientific lines. Apart from the various research programmes that are being carried out in our Surya Jyothi Project and Anveshana Project, we feel there is an enormous amount of work which needs to be done. A few important activities that are of immediate concern are noted here:

- 1) To bring out a profile of the mentally handicapped and their families who seek professional help from our institute. This will be on the basis of the rich data that our records hold. Such a study will provide a valuable feedback for our community awareness building programmes and various community based care programmes.
- 2) Indian Families have tremendous resources and manpower embedded in them for the rehabilitation of the mentally handicapped such as grand parents, siblings etc. The necessities of life, forces both parents to go out for work whether in the rural area or urban area, with little time even to cater to the needs of the normal children. More so they tend to neglect the handicapped children as they feel that there will be no returns. It is in this context the training of siblings, grand parents and other family members who could spare time for the training of the handicapped child arises. With this in view we plan to undertake an experimental study of involving siblings in the care and training of the mentally handicapped on the basis of which strategies can be worked for future.
- 3) It is planned to undertake a comparative study of the impact of the special training of the mentally handicapped children: Children under foster care home care vis-a-vis children coming from their own home.

This would help to bring in suitable modifications in our foster care programmes and test the efficacy of the foster care home.

- 4) There is a need to conduct a pilot study on the Community Participative Rehabilitation programmes for the mentally handicapped.
- 5) Knowledge and opinion survey of the school teachers regarding the integration of the handicapped with the normal children should be undertaken.
- 6) Very little is known about vocational rehabilitation. There is need for research to solve not only current problems but also those which may arise in the future. We need to collect data on the effectiveness of methods so far used. We need research in adaptation of jobs, and safety of disabled workers. Adapting jobs for the disabled calls for creativity and imagination. Industries may be asked to fund such projects.
- 7) We need to undertake research to evolve an effective media of communication for awareness building.

### **Other Projects:**

*The other major programmes we have in view are:*

- 1) Periodical detection of the mentally handicapped children from the certified school for boys and girls and plan for their rehabilitation.
- 2) Education of the school teachers regarding mental handicap so that children are identified and referred to us when he/she is 8-10 years old.
- 3) To take-up some practical and viable steps towards the integration of the disabled children, especially the mentally handicapped in the normal schools.

### **Education & Public Awareness:**

Communication is vital to detection, rehabilitation and prevention. The fact is that people with disabilities are not within the research of available services. How are we to reach them? And how are we using the media - to reach the public - who are not directly affected but whose attitude and behaviour help determine the quality of life for the people who are disabled. The answer is Education and creation of public awareness pertaining to the prevention, facilities available for early intervention and rehabilitation.

Education and Public Awareness will encourage self-awareness, informed decision-making and appropriate action. Such effective programmes can and do make a dramatic difference in decreasing the incidence and prevalence of mentally handicapped in our country and overall as preventable factors contribute a larger share in the generation of disability in our country as well as other developing countries.

Young and old people must be made aware of the vital link between their health and the eventual well being of their children, the hazards of early marriages consanguineous marriages.

Prevention education can assist in ensuring that all young people have the knowledge, awareness and attitudes necessary for responsible parenthood and preventive health care. A comprehensive prevention curriculum should be a regular part of the State's education programme for students of all ages in public and private schools and colleges. It should be included in continuing education too.

The dissemination of knowledge should also be tailored to the needs of specific target populations—high-risk group, adolescents, low socio-economic population, slum dwellers, rural folks etc. Written and audio-visual materials, along with the professional training programmes, workshops, seminars, professional publications, public service announcements and indigenous media such as folk songs, burrakata, role-plays, etc., are extremely useful in educating the public. Materials and presentation should be available in regional languages. Television and radio are excellent vehicles for reaching the general public as well as the targeted population. These public media should be considered for use in dissemination information through regular programmes during the day time and the “prime time” hours.

### **Challenges before are:**

Determining what messages should be conveyed to what particular type of audience and in which form. Optimum utilisation of the existing media and conveying the correct message poses the second major challenge to be worked out.

### **Camp Approach:**

As a part of human resource development programmes we have conducted several Rural Camps through our Clinical teams without any expenditure through resource mobilisation identifying resource centres Balasevika Trainees, Balwadi Creches, Public Health Centres in collection of data, dissemination of information and supply of Health Cards for further follow up.

### **Personnel Development:**

Another challenge that we face is in the area of manpower development. For any rehabilitation plan to be effective, knowledgeable and capable individuals must be available to develop, implement, and maintain that plan. The number of individuals (professionals, para-professionals and parents) currently trained in the area of prevention, intervention and rehabilitation is limited. The resources for personnel development must be identified and encouraged, the tools for training should be developed, and a proper monitoring system should be evolved.

Our immediate plans are to train the grass root level workers, the balwadi teachers, Creche workers and the trainers of these balwadi teachers. A few diploma programmes to train physiotherapist in developmental therapy to spread our innovative methods on early identification are also planned by us.

## Challenge for the Future:

Health promotion, prevention of diseases, early detection of disability, early intervention, rehabilitation community based care, integration of the disabled are not static processes. Its pattern of services and programmes must continue to change with the thinking and practice in the coming years. No simple blue-print of future development can be readily sketched at this point of time. Hence, no single approach to all these programmes including technology, delivery system and management would be applicable in every part of the world. Every country should decide its own plan on the basis of its specific needs, and experiences gained from abroad and lessons learnt at home to ensure a life of dignity for the disabled. No amount of recommendations or resolution can makeup for positive action. It is necessary to prevent disability now, treat handicap immediately and train and rehabilitate the disabled today. Yes, it can be done, It requires political will, determination and clear goals and perspectives. The fact is that the attitude and vision we have to determine whether we are successful in meeting the global challenges of helping the disabled "Anveshana" - Rural Project - 1985 - 1988.

### Results (1985 - 1988):

Total population surveyed.....	17671
Total families covered .....	2940
Total children enumerated.....	7068
Total disabilities identified (survey) .....	801
Other diseases .....	383
No. of Nutritional disorders .....	382
Total disabilities in children .....	782
Followed up	
No. of disabilities referred to THPI specialists for consultation	749
No. of other disabilities referred to other specialists .....	286
No. of disability cases treated successfully .....	405
Total no. of drop outs .....	33
Other diseases cured .....	203
No. of children integrated in the balwadis .....	73
No. of children in the process of integration .....	301

Total No. of visits by THPI team .....	107
Health Education camps .....	113
Total women benefited from the camps .....	1029

We had found many children in danger of becoming disabled, they were cured or improved considerably or are in the process of integration and the required follow-up. Three children died following malnutrition and subsequent infection because the families were not interested and did not head to our advise to get the children treated. Therefore the need of the hour is to inform the public and educate them about the needs and facilities provided for the mentally handicapped. The THPI is one of the pioneering institute in the process in the country. We hope to keep the flag flying in the decades to come.

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# National Programme on Rehabilitation of the Disabled

## **Introduction:**

People with disabilities in rural India, have not been reached for appropriate effective rehabilitation services barring some genuine initiatives by Voluntary Agencies who have “gone rural” in the real sense. Though the DRC scheme was launched with an ambitious objective of providing rehabilitation services in rural areas in 1985, the bureaucratic nature of the organisation and style of functioning of the DRCs which kept community involvement (people’s participation) and inclusion of Voluntary Agencies on a low ebb, ushered in outcomes that were far from satisfactory. Therefore, when the Nation is entering the Golden Jubilee year of its Independence, the initiative to launch a National Programme focusing on the Rehabilitation needs of the rural population with disabilities is quite heartening. The proposal needs to be studied to project realistic outcomes based on factual data in the existing scenario and assumptions that are not over ambitious but optimistic. A cautious and usable approach to operationalisation of its objectives may result in maximum benefit to the ultimate consumers — people with disabilities. Bearing this fact in mind, the proposal is being reviewed.

## **Inclusion of People with Disabilities:**

Self advocacy and consumer awareness that have empowered people with disabilities globally, have made Human Services to recognise and restructure their programmes and strategies “**Nothing about us without us**” a slogan which is popular in movements organised for and by people with disability, seeks their active participation in making decisions relating to them. However, in the national Programme for rehabilitation of the disabled, there is no representation of people with disabilities or their families in any of the advisory committees, right from the Grampanchayat Level to the National level. The philosophy of CPR emphasizes empowerment of people with disabilities and their families through active participation. The proposal does not mention that priority will be given to people with disabilities among candidates who meet the eligibility for the posts. As a programme of the Nodal Ministry in matters relating to disabilities, the need to involve and also employ people with disabilities whenever possible, needs to be emphasised in the National Programmes for disabilities and rehabilitation.

## **Nomenclature:**

It would be advisable to name programmes in a manner where the fact that the beneficiaries are "People first" is recognised. Disabilities are only a part of these people and they do have some capabilities as well. It is therefore suggested that the programme may be named as National Programme for Rehabilitation of People with Disabilities (NPRPD). The nomenclature must also meet the global trend at least for new programmes that are on the anvil.

## **Coverage:**

The phased programme in 32 districts per annum covering 160 districts in a plan period, leaves a long wait of over two more Five Year Plans for a total National Level implementation in 507 districts. With a projection of one lakh of persons with disabilities to be added annually to the existing population. Can the nation wait for a huge outlay programme to be piloted, evaluated and replicated in for 15 years? A serious thought in this direction is called for. Even after 50 years of non-contemplate on small scale coverage with a meagre outlay, most of which is diverted for infrastructure and salaries for personnel in districts and urban cities in the State (DRCs, RTCs, SIDRs, NGDR etc.)

## **The Budget:**

Nowhere in the proposal, a tentative estimate of the total number of persons with disabilities likely to be served through the first phase of NPRPD is mentioned. Similarly the number of people already reached by services is not provided, so that the proposed programme could target the unreached people and also eliminate duplication of services. CPR is a programme that is tailor-made to meet the specific needs of the specific unit. India has a heterogeneity among its states in the levels of awareness, availability of existing services and infrastructure of NGO's prevalence of disabilities, geographical area and population and therefore harping on uniformity in programme structure, and equal distribution of resources will result in disproportionate resource allocation in terms of the needs.

Based on projection of population for IX Plan (95 crores) and the prevalence rate of disabled persons i.e. 3.9 per cent as per information in the proposal (1.9% of 4 disabilities and 2% of M.R. = 3.9%), the budget appears to be an underestimation even if we delete the 10 per cent of the 3.9 per cent as people already receiving services. It can be clarified through the following details.

## PART - A

Population projection for IXth Plan	95 crores
Number of disabled people @ 3.9% i.e. 4%	3.80 crores
Assuming that 10% are already reached	0.38 crores
By existing programme, the target would be	3.42 crores
Total Number of Districts in India	507
Total Number of Districts to be covered in 1st phase	160 (31.5%)
Budget outlay for 31.5% (Recurring + 50% of Nonrecurring @ 10% Depreciation)	32950.64 lakh
Therefore 100 percent coverage of districts excluding margin for escalation of costs $32900.64/31.5 \times 100 =$	1044.05 crores

## PART - B

Available estimate on expenditure for rehabilitation of 10,000 disabled persons at the rate of 10 per cent disability	Rs. 1 crore
Therefore estimate for 4% of the 10% disabled persons is (4000 persons)	Rs. 25 lakhs
Therefore the total cost for National coverage $2500000 \times 3.42/4000 =$	Rs. 2138 crores

Even considering a minimal coverage of the population of people with disability at the rate of 4% the project budget of 1044.05 crores for the entire nation is far below the bare minimum required. A major part of this budget also will be diverted to salaries and infrastructure building, leaving a very little allocation for real rehabilitation services.

### Human Resource Requirement:

The multi-tier system of service - delivery involving trained personnel and the development concurrent training machinery and infrastructure envisioned in the project proposal is very appealing. However, are we realistic about the requirement of a large number of trained therapists

and professionals to be associated exclusively with this programme? Paucity of training facilities in the country coupled with the attraction of overseas job placements have literally drained the nation of trained human resources in the disciplines of Clinical Psychology, Speech Therapy, Physio and Occupational Therapy. Presuming that the short-term certificate courses and diploma programmes of SIDR would create grassroot level functionaries, can the SIDRs at each state level have Master Trainers, Professors, Assistant Professors, Lecturers etc. in the different disciplines considering the brain drain that prevails in the country.

Convergence is the key to making CPR programmes cost-effective. Can India afford parallel programmes of training when there are constraints of resources? Alternatively it is recommended that the SIDRs may assume to role of a State-Level coordinative mechanism and delegate the training and research to the Universities, National Institutes and their regional-centres and competent NGOs who have the infrastructure and the faculty in each state. More thoughts need to be given to avail the services of grassroot level functionaries of ICDs, BSTIs, multipurpose health workers etc. Rehabilitation needs a humanitarian approach to the problems of people with disabilities. Due recognition should be given to the befriending and endurance, willingness and commitment of the of the grass root worker in addition to monetary incentives. The criteria of selection must have provision to incorporate the said qualities in the field level functionaries and at all levels the local NGOs must be approached to assist in identifying suitable candidates.

Standardisation of curriculum and the monitoring of quality of inputs will ensure preparation of effective personnel.

Whenever possible, already available trained human resource and infrastructure can be identified and utilised through effective linkages rather than create posts which involve recurring and nonrecurring resources. The services of Master Trainers can be availed as guest faculty, or as short term deputies from National Institutes or Voluntary Agencies.

### **People's Participation and Involvement of Community:**

The proposal has not given due consideration to the importance of involving the community in the programmes though it is considered a CPR programme. Rural India is not devoid of voluntary support for programmes which benefit people. The success of any large scale programme depends on peoples participation. The National Pulse Polio Programme (though a belated effort of the Government of India) stands as a striking illustration of how voluntary organisations, various Government departments and above all the people of India have worked in unison for Polio eradication. The role of Mass Media in campaigning for the cause also needs to be acknowledged.

The project professes to implement the programme with its own, bureaucratic machinery with a very casual mention of NGO's participation. The indispensability of NGOs as partners in the process of Rehabilitation has been universally acknowledged. Already many voluntary organisations are involved in CPR programmes which have utilised less resources and depended more on the resourcefulness of the community. Taking NGOs with good standing into confidence and involving them as partners in the implementation of the programme is imperative. Clear guidelines need to be evolved on the supplementary and complementary role to be shouldered by Voluntary Organisations and the Government.

### **Impact of the programme:**

Regular evaluation and feed-back mechanisms have to be built in from the very commencement of the programme at all levels. Irrespective of the number of people with disability reached by the programme, there should be ways in which the programme could evaluate the progress in their quality of life. How far the programme provides equalisation of opportunities and services and protects the Human Right of people with disabilities must be examined with regular periodicity at every level.

Rehabilitation process in the programme should not be confined to mere "cure" or "Care" strategies in segregated settings isolated from the mainstream. As citizens of the nation, people with disabilities must be provided access to all national level programmes and their inclusion must be ensured through effective monitoring systems.

### **Programmes for people with Mental Handicap:**

Universally the practice of categorising people with disabilities is not homogeneous groups is fading. Recognition of heterogeneity based on the etiology. The ecology and the attitudes for the community in which they live has necessitated flexibility and diversity in support systems.

The unique needs of people with mental handicap are minimally catered to as far as job placements and employment are concerned. In spite of the absence of mandatory provisions for reservations of jobs in the Public Sectors, many have proved beyond doubt that they can integrate into the work force of organisations, business houses and small industries if supported appropriately. Strict adherence to their provisional diagnosis (Purely clinical) based on IQ without recognising their functional capabilities, has eliminated many of them from access to VRCs, Special Employment Exchanges etc. Preconceived notions of 'unemployability' of many of them who can execute several jobs though they may not have the academic record of X standard of VII standard is a discrimination towards people who have difficulty in scholastic tests and examinations. Special provisions to enable the economic rehabilitation of people with mental handicap needs to be incorporated.

The programme, therefore must focus on mobilising suitable infrastructure, personnel, awareness strategies, intervention facilities adequate resources etc., to ensure a qualitative rehabilitation for persons with mental handicap. Measures to eliminate discrimination have to be intensified to undo the isolation meted out to them in provisions for rehabilitation in all avenues - education, employment, social inclusion ad participation.

**Conclusion:**

The vision to reach people with disabilities in the rural areas through a National programme on rehabilitation is quite fitting and proper when we are on the threshold of the 21st century. A word of caution is that it should be a mission which involves the Governments, Central and State, Voluntary organisations and the people from all walks of life who can be effective contributors, so that the available meagre resources may be used to the maximum benefit of people with disabilities.

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# Caring for the Disabled: Needs of Developing Countries

Social Development goes far beyond the mandates of Social Welfare Policy. It lies in the heart of economic development, of Human Rights and of Peace and Security. Let us therefore use creative approaches, all the while trying to find concrete solutions. More than 350 million people with disabilities live without the help they need to enjoy a full life; they live in every nation, but by far the greatest number live in countries in their early stages of economic and social development.

In a country of India's size and diversity, wherein participative democracy is sought to be promoted, aspirations have become virtually universal. But owing to paucity of resources, opportunities are limited that make prioritization complicated. There is also the problem of matching quality with quantity. With the constraint of resources, need and benefit can not keep abreast.

However, the indicators of socio-economic needs, commonly termed backwardness or under development, can be used to identify the priority areas, focus more on needy target groups in critical conditions and to put together a need based integrated package of programmes and services.

The 'needle of priority' as it were, points to the spots, on which three factors converge viz., a backward area, a category of children at high risk (critical need) and need-based but cost effective programme.

Child Development must be a Central objective of any meaningful National Developmental Policy. Although the Health Infrastructure in India with over 22,000 Primary Health Centers, 1,30,000 Sub Centers, 2000 Community Health Centers, over 5,00,000 trained birth attendants and 4,00,000 of community health guides-is by no means unimpressive. The fact that despite these impressive investments, the country is still far from its goal in the field of child health care, points either to some basic flaws in our strategies or to serious shortcomings in implementation. A multiplicity of overlapping uncoordinated programme there borne not out of any Grand design, or a coherent out-reaching National Child Development Policy.

## **Lack of Community Participation and Public Cooperation:**

Despite frequent lip service to the importance of community participation we have not really succeeded in enlisting the informed participation of the community in health welfare

and child development programmes. This has resulted in lack of accountability and poor utilisation of available services. The present psychological distance between the Provider and the consumer needs to be bridged. The involvement of rural schools in community upliftment programmes for rural youth can transform the situation. Through such community organisations we may be able to bring about meaningful functional integration and reinforcement of the multiplicity of welfare programmes meant for rural communities.

The critical need is to provide an enabling measure to open up the normal potential of development. There is a need to design a complementary Community Programme which needs institutions as referral stations and technical support base. These differences may seem artificial but they have substantial implications for the development of rehabilitation policies and the allocation of resources and staff.

The basic pre-requisite for any outreach concept is the availability of a developed infrastructure upon which the programme can build. Only communities which are within direct reach of Governmental and Non-Governmental agencies will be able to benefit from services they can render. This means that such communities must be linked to the outside world through road, rail or river and that some type of regular transport like bus, truck, train, boat or other means must be available.

Each plan should clearly define the goals and objectives as well as the specific strategies and actions that will be required for implementation. We think it is very important that the plan be written at an appropriate reading level to make certain that the targeted audience, including professionals and consumers (the general public) understand its contents.

One of the first steps in the planning process is the clarification of authority within the state and identification of the responsible agency who will take the leadership role in organising and writing the plan. The planning group should include representative of many professional disciplines, and persons representing agencies and organizations who provide services and who will be responsible for implementing portions of the prevention plan. It is important to obtain input from consumers, parents and voluntary agencies at all stages of planning.

### **Needs of the Developing Countries in the area of Mental Handicap:**

In contrast to the developed countries, India does not have a well developed and universally available health care, education or welfare services. The needs have to be seen from the point of developing services in India in Human Rights, quality of services, professionalisation of care etc. The needs in India have to be considered both from a macro level to a micro level initiatives.

## **Macro Level Issues:**

1. Legislative provisions for disabled care.
2. Well articulated and funded services for basic health, education and welfare services.
3. Improvement of overall living standards.

## **Needs of our Country:**

### **I Middle level needs:**

1. Development training etc., of professional personnel
2. Institutional settings for tertiary care
3. Research into causes of mental handicap
4. Local initiatives for primary prevention, and secondary prevention
5. Innovative models for care utilising community resources
6. Media campaigns.

### **II Micro level needs:**

1. Strengthening of the family with handicapped persons.
2. Employment/vocational support.
3. Community level programmes in rural areas.
4. Integrated education for the disabled.
5. Public education and acceptance by general public.

## **Immediate needs:**

### **1. Human Rights:**

The constitution of legislation and other guarantees of equalisation of opportunities for people with disabilities.

### **2. Adapting Environments:**

Incorporation of accessibility into building Codes and other laws and the eradication of design elements which create physical dependency on others for mobility.

### **3. Disabled women:**

Equalise the involvement of disabled women to that of disabled men in all services and programmes.

#### **4. Employment:**

Support job creation, self-employment, small scale industry opportunities for disabled people, and reduce reliance on Sheltered employment and other traditional approaches.

#### **5. Policy Development:**

Design comprehensive national policies on disability, acknowledging its legitimate place in the life-cycle and its relationship to other broad development issues, such as the aged, women, the environment etc.

#### **6. Education & Training:**

Intensify involvement of disabled children and adults in education and training programmes from the stages of early intervention through university level.

#### **Children:**

Implement U.N. Convention on the Rights of the Child particularly with regard to children with disabilities.

#### **Public Education & Media:**

Take concrete actions to promote the acceptance of mental handicap to the social media and educational curriculum. The child with disability is first and foremost a child. The education of such children for leading normal life in the community in our nation demands not merely the achieving of academic skills, but also a vast array of socialising experiences. Restricted and restrictive social opportunity and experience results in restricted knowledge in critically important life-skill areas. The legacy of segregated educational provision for disabled children has in many instances exacerbated schooling problems and compounded problems of social distance through its negative effect on community attitudes.

#### **Need for special effort for disabled people:**

Disabled people in our country are among the poorest and most deprived people in terms of educational and employment opportunity. Among the aims in assisting disabled persons should be dissemination of elementary and easily accessible information, with a view of eliminating a number of prejudices against them. The more disabled persons are given access to training in a society, the more the rest of the population will learn to respect all disabled persons.

#### **1. Need for Early Identification, Early Detection and Intervention Programme for Prevention of Disability:**

The earlier the identification is made, the better it is, as it will facilitate the provision of early stimulation and being brought up within the framework of an individualised management

programme which is so very essential. Simple tools of identification need to be made available. There is a need for well equipped neonatal intensive care units.

## **2. Services:**

In our country services of rehabilitation and special education are available mainly in large urban cities. But the majority of the population lives in the rural areas where there are hardly any services. The Community Level Rehabilitation model has been tried with limited success at few centres. The ultimate success of this programme is yet to be tested and achieved.

## **3. Training of the Trainers:**

Training packages need to be developed for training the trainers at different levels i.e.:

- 1) for professionals working with disabled;
- 2) professionals not trained in the rehabilitation process so that disabilities can be detected at an earlier stage;
- 3) training of para professionals and community health guides;
- 4) people who come across the target population like teachers from normal schools;
- 5) village leaders. The training programmes need to be of different durations i.e., long term, short term etc.

## **4. Adaptation and Translation of Techniques and Technologies to Local Conditions for the Benefit of Disabled:**

Development of science and technology in our country for the disabled is in its infancy. There is need for more innovative and creative thinking for development of methodology and application in this area. Facilities should be developed for assessing the residual ability of persons with disabilities so that skills can be best utilised. Adaptations for machines and equipment should be opportunities of persons with disability. For sharing information on availability of the technology, publications need to be brought out for wider dissemination.

## **5. Assessment, Curriculum and Instruction:**

Throughout the Developing World there is an absence of a suitable text book describing the method of testing and teaching the Disabled. Text books from the developed world are often inappropriate due to cultural bias. There is a need for field based research which is the answer to developing of locally valid testing and teaching methods and materials.

## **6. Vocational Training and Employment Opportunities for Disabled:**

Vocationalisation has not yet taken deep root in our country. Separate institutions should be set up for imparting vocational training. Till recently no effort has been made to place disabled people in suitable employment. Special employment exchanges have been established. Employment of people with disability on competitive term is a concept of recent origin. Systems need to be evolved so that people with disability do not have to beg nor live on charity but opportunities be given to them to be productive so that they can earn their own livelihood. There is a need to work out a different model for mentally handicapped persons specially in rural areas since they cannot travel long distances for employment. This model has been successfully tried and implemented in India by Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped Persons, Hyderabad and Thakur Hari Prasad Institute Rural Project, Lalacheruvu, India (A.D.C. Project).

## **7. Disabled Persons and the Legislation:**

A comprehensive law "The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995" was enacted by Parliament and has been enforced with effect from 7.2.1996. The Act covers right to education, training, employment, prevention and health and over all rehabilitation of the disabled. Discrimination against disabled should be prohibited. Certain special facilities should be provided to them, special privileges with regard to taxation including Income Tax and Wealth Tax is desirable. Needs of disabled women should be taken care of.

## **8. Alternate Social Security Systems:**

With economic constraints, no developing country can afford to create State sponsored social security system for people with disability. Even parents of children with mental retardation who willingly look after the needs of people with mental retardation in their lifetime often ask this question as to who will look after their child after the parents are no more. As an answer to this, the Government of India has proposed to create a National Trust which can take up the guardianship of people with mental retardation and cerebral palsy after the death of the parents. The National Trust for Welfare of the Handicapped which is before the Parliament for clearance is one of the recommendations of the National Seminar organised by Thakur Hari Prasad Institute, Hyderabad, India.

## **9. Community-level Rehabilitation and outreach programmes for inaccessible areas:**

There is a pressing need for ruralisation. The problem is how to spread services taking into account constraints of both resources as well as trained manpower. There is a need to

make rehabilitation services available in greater measure for the poor. The frame-work of Rural Programmes should comprise of

1. Awareness/sensitisation on the lines of Rural camps conducted by Thakur Hari Prasad Institute Rural Project, Lalacheruvu, India for creating awareness in rural areas by the cost-effective method of utilising available manpower and infrastructure)
2. Identification - Door to door survey conducted by utilising available infrastructure.
3. Information dissemination
4. Motivation
5. Evaluation
6. Monitoring and sustained follow up. Suitability is most crucial even after initial support is withdrawn Anveshana Project" on prevention, early identification and intervention of disabled" launched by Thakur Hari Prasad Institute, Hyderabad, India and still under successful operation is a model in this regard.

## **10. Strengthening Families:**

In most developing countries, the burden of caring and training children with disability particularly Mentally Retarded persons, primarily falls on the family. We have to therefore promote family oriented services, through Centre based individual model, Centre based Group activities, Parent-professional meetings, family cottages, parent to parent support, Group parent training programmes, Sibling groups, parent self-help groups, promoting cooperation among parent organisations etc.

## **11. Role of Media in Creating Awareness:**

Media plays an important role in the society today. Awareness about disabilities and the potential of persons with disabilities needs to be created among families of disabled persons, community planners, decision makers, employers, academicians etc. Print media along with the electronic media i.e. Radio and T.V. and traditional media will have to play a very important role. Media can play an useful role in disseminating information about disability to the general public, removing myths in the mind of the people regarding disability, educate public about the abilities of the disabled. (A series of Media Seminars were successfully conducted by Thakur Hari Prasad Institute, Hyderabad, India in collaboration with National Forum for Welfare of the Mentally Handicapped Persons).

## **12. Information and Documentation Centre:**

There is a need for establishment of information and Documentation Centres which can be approached for information on available training Institutes, job openings for disabled,

publications, locally manufactured support appliances and teaching materials, Educational Assessment and Resource Services, well documented and detailed guidelines for Planning, Implementation, and Management of programmes, specific schemes from different departments of Central and State Governments, International perspective, research and development.

### **Implementation Measures:**

States should assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

1. States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.
2. States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities. They should bear in mind the need to protect individual privacy and personal integrity.
3. States should initiate and support programmes of research on social, economic and participatory issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.
4. States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.
5. States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.
6. States should support the exchange of research findings and experiences.

*NGOs / THPI*

# Role of Non-Governmental Organisations in Developing Countries

## 1. Introduction:

The significant roles played by major NGOs and the contributions they are currently making in the care and rehabilitation of persons with disabilities can never be erased from the history both in developing and developed countries. In India, NGOs have always been in the forefront in responding to the ever challenging rehabilitation needs of persons with disabilities in myriad ways. Though voluntary service care for disabled persons had its origin decades back, NGO action in the field of Disability Prevention, Rehabilitation and Inclusion has become more spectacular since a decade and a half. Contributions of NGOs in providing quality rehabilitation services and in reaching the unreached in rural and tribal areas through its various innovative strategies remained unmatched by Government action. By doing so NGOs have not only played a complementary role and supplementary role but sometimes the main role in the rehabilitation of persons with Mental Handicap.

This paper is based on the premise that there is no substitute for voluntary social action and so there is no limit to the various developments an NGO can initiate and sustain. This premise has been substantiated by facts and experiences of a premier NGO in India - Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped. The various initiatives in terms of services and service modules evolved to suit the needs of rural and urban populations, human resources tapped and trained, awareness created through innovative, effective, local media, specific experiments carried out in certain challenging areas viz., employment of adult persons, integration of children in the existing educational institutions (Pre-school onwards), early detection and intervention and so on, form the base of the data. THPI's role in policy formulation and pressuring the Government for social audit and many other steps at national level are also discussed.

## 2. The Contextual Background:

The significance of THPI action has to be viewed against the contextual background, the socio-economic and political pressures amidst which it had to work. It is easy to bring about changes or cause dramatic developments when the environment is congenial and encouraging

but not when one has to work through tremendous foreboding pressures and swim against the tide.

- Around 10 percent of the population are affected with some disability out of which 3 to 4 percent require special care and attention.
- More than 2 per cent of the population are affected with M.R. which requires immense support.
- In India as in other developing countries, the major causes of disabilities are malnutrition, communicable diseases, infections in childhood, accidents at home and at work.
- About 70 per cent of people with disabilities who live in the rural areas (who then are at risk of the factors mentioned above) are marginalised and disadvantaged because of a variety of factors viz., poverty, ignorance, illiteracy etc., leading to lack of access to productive resources, opportunities, information and skills.

Moreover, some groups of disabled persons are more marginalised than others i.e. persons with mental handicap.

- Initiatives taken by the Government and NGOs remain urban-based and welfare-oriented. It is estimated that only 2 to 3 percent of persons in need of rehabilitation have access to these services.
- Lack of knowledge and misconceptions about disabilities in general and mental handicap in particular prevail at all levels right from the policy makers down to the family members of the mentally handicapped.

Many people cannot differentiate mental illness from mental handicap. 'Handicap' is understood more as 'physical handicap' and there is no proper understanding on the different types of handicap let alone mental handicap.

- Though disability, is a State subject there has been no initiative from the States to address this issue.
- India is a signatory of the global declarations of UN standard rules for Equalisation of opportunities in 1982, Regional Salamanca Declaration on Education for All, UN Alma Atta Declaration of Health for All and so on — we have participated in the International Year of the Disabled and are now, in the midst of the Asia Pacific Decade of the Disabled (1993-2002). In spite of all these declarations our country still maintains a snail's pace with regard to rehabilitation programmes for disabled persons. It struck only THPI to have a mid-term review of the Asia Pacific Decade on 16th July, 1997 at New Delhi at its own cost.

Given these prevailing conditions, on the NGO action in terms of the certain crucial aspects towards the rehabilitation of persons with Mental Handicap are discussed. They include:

- i) Quality of service and models
- ii) Reaching out to Rural Areas
- iii) Utilisation of Available Opportunities - Convergence
- iv) Awareness Creation
- v) Role played at National and State Level
- vi) Human Resource Development and Research

**i) Quality of Service and Models:**

This needs to be viewed again with reference to the prevailing context. When THPI started in 1967 there were hardly any NGOs in the country catering to the rehabilitation of persons with Mental Handicap. Though we have around 300 institutions in the field today, most of the institutions run on the lines of day care centres with some Special Education inputs. It is only a handful of institutions which have the provision for Vocational training. Vocational training where it exists, is provided more as a recreational activity or something to keep the adults "engaged" than as a meaningful training with a long term perspective leading to employment of persons with Mental Handicap in the open community. We also had no text book answers to the 'how' of the rehabilitation of these persons. It is in this context that as early as in 1967 THPI visualised the need for a multidisciplinary intervention towards the TOTAL REHABILITATION of persons with Mental Handicap. Therefore, from day one it started with a full time multidisciplinary team for the special training of persons with Mental Handicap. Just every possible intervention strategy available has been tried and regularly imparted. The therapeutic interventions include Special Education, Behaviour Modification, Occupational Therapy, Physio Therapy, Speech Therapy, Family Intervention, Medical Care, Psychiatric Care, Yoga Therapy, Hydrotherapy, Music, Dance, 'Mridangam' creative and performing arts and so on. What is important is, however big or small each programme is, it must be subjected to a well discussed plan, systematic implementation, periodical review and updating. No programme can be taken for granted and so too service modules including right from preventive education to early detection, early intervention and integration to special education, vocational training, employment and integration in the community. The focus remains, the OPTIMUM DEVELOPMENT of persons with mental handicap through ALL POSSIBLE MEANS. This resulted in the development of some of the most viable innovative service models such as Foster-Care Home as an answer to 'what after the parents are gone'? Social Integration model which was accepted by the Planning Commission and Ministry of Education for nation-wide replication,

empowering adults through employment (another major break through in the history of rehabilitation) neighbourhood integration, rehabilitation of children under judicial custody, low cost teaching aids and so on. It can be said without exaggeration that the Thakur Hari Prasad Institute is a pioneer and perhaps the only institution in India with all the facilities of multidisciplinary team and interdisciplinary inputs under one roof. Moreover each and every service implementation is backed by adequate planning and systematic review.

This was possible not because of a well structured plan or guidelines which were available to us as in a Governmental setting, but because of the urge, passion and commitment towards exploring and doing ALL THAT IS POSSIBLE, so that the optimum development of persons with Mental Handicap towards AS INDEPENDENT A LIVING AS POSSIBLE take place.

**ii) Reaching out to Rural Areas:**

It has become fashionable to talk of 'GO RURAL' these days, but no one really means it. Given the immensity of the problem of more than 80 per cent of persons with Mental Handicap in rural areas and who cannot be reached by any Professional Service, they are exploited or misguided by the local health practitioners and faith healers. These disabled persons are the ones who were never given an opportunity to develop their innate abilities. It is THPI which first came up with an answer to the problem by establishing a Rural Community Participative Rehabilitation Centre in Lalacheruvu, East Godavari District of Andhra Pradesh. This centre with a full time multidisciplinary team to cater to the needs of the mentally handicapped persons in the rural and tribal areas remains first of its kind, with its community-based training services, human resource development modules and awareness creation strategies. The main focus is on CONVERGENCE OF SERVICES, LOCAL PARTICIPATION, LOCAL SUITABILITY, AVAILABLE AND AFFORDABLE REHABILITATION MEASURES. This centre has developed viable and sustainable strategies to reach out to the whole of East Godavari District. It is equipped to provide consultancy services in rural community level interventions. The centre does not advocate just one model or a single approach, but a flexible package that combines various strategies to suit the local needs and situations of the rural people. This project proves beyond doubt that SUSTAINED DEVELOPMENT is possible if the community is adequately empowered for participation.

The outreach programmes of THPI in 23 neighbouring villages is another example of the sustainability of programmes long after the withdrawal of active professional support. Factors that account for success are COMMUNITY PARTICIPATION, NETWORKING OF LOCAL RESOURCES, CONVERGENCE OF SERVICES SUPPORTED BY AWARENESS BUILDING AT ALL LEVELS. Integration of children through local balwadis (a mainstream provision) which was practiced through 300 centres integrating around 1500 children, employment of adults through local work trades (wherein hundreds of adults are employed in rural areas) are some

of the measures taken towards optimum utilisation of available resources. But this was possible because of the painstaking efforts of many professionals towards promoting community participation and local resource mobilisation.

District Rehabilitation Centres initiated by Government have failed when it came to eliciting community participation and this has had a telling effect on the effectiveness and sustainability of programmes. The DRC - experience is a clear indication of the need for "human investment" for the success of any rehabilitation programme, an NGOs are endowed with this capacity.

### **iii) Utilisation of Available Opportunities – Convergence**

We need to cater to a wide variety of parents. It became difficult for parents of lower middle and lower economic groups to afford or follow-up the training programmes using commercial teaching aids. In our attempts to make education accessible to every parent even the poorest, various low cost indigenous methodologies have been evolved viz., indigenous teaching aids, integration of children through local balwadis, employment of adults through local jobs etc. Through these we have not only succeeded in tapping the available channels for the rehabilitation of persons with mental handicap, but during this process we also educated the family members, the community, the local leaders and other local functionaries. It had a multiple impact.

For a country like India with the magnitude of its problem and scarce resources it becomes all the more imperative to use existing channels for awareness building and in carrying out of rehabilitation services. A Children's International Summer Village Camp (CISV) and a National Learn-to-Live Together Camp was conducted by Indian Council for Child Welfare for experimenting on integration of mentally handicapped children. Utilising the international camp participants for a RUN for the mentally handicapped created wide publicity in the state and the international community.

The block placement of the 'balasevikas' (pre-school teacher trainees) for a house-to-house survey on disability and awareness creation on mental handicap, utilising every function of THPI as an occasion to sensitize 'people in power' by involving them as Chief Guests or Guests of Honour are some of the strategies adopted. Conducting of these programmes was not as easy as it sounds. A tremendous amount of foresight, innovativeness, and perseverance was called for and this was forthcoming because of an undivided commitment to the cause.

### **iv) Awareness Creation:**

Given the magnitude and depth of lack of awareness, misconceptions and negative attitudes prevalent towards disabled persons in general and mentally handicapped persons in particular, it was essential and imperative to educate people at all levels right from the policy makers down to the families of persons with a mental handicap. Children with a mental handicap are hidden in their homes out of shame, fear of social ostracism and due to other misconceptions

and taboos. Some of them were starved, chained or beaten up because mental handicap is considered as being 'possessed of evil spirits'. In some communities these children were worshipped as they were considered 'Gifts of God'. The result has been that these children were denied the opportunity to develop their abilities and participate in society. Therefore huge investments in terms of money, human resources and time had to be made in our efforts to EDUCATE THE PUBLIC AND SPREAD AWARENESS. Every effort made by THPI, however big or small had a deliberate purpose in educating one target group or other. For example, the big event in organising the XI World Congress of ILSMH on Mental Retardation in 1994 which brought members from 102 countries to deliberate on various issues on Mental Retardation was not for fun and frolic or for the thrill of organising a global event. This world event which was held in the capital city of the country created sensation all around the capital and in India on the whole. If not completely successful in educating the target group, it at least opened the minds of hundreds of policy makers, media persons, politicians, professionals, parents and advocates to think of this problem.

Similarly realising the potency of media in creating awareness (as India has a wide coverage of communication network—the radio and TV covers more than three-fourths of the country) a series of MEDIA SEMINARS were organised in different parts of the country during 1991-1992 (at Hyderabad, Delhi, Bombay and Calcutta). This resulted in sensitizing the media persons and in creating a positive attitude towards persons with Mental Handicap. There has been a marked 'inclusion' of mental retardation in all the National Media. The strategy now has been adopted by the Government too. This programme has also attracted the attention of the Ministry of Welfare for funding through its National Institutes.

Numerous other media, indigenous and otherwise were used for creation of awareness and educating the public, both rural and urban. A tremendous amount of positive impact was created. The lesson we learnt was that there is no limit to the forms of media that can be made use of, what is important is commitment towards the optimum utilisation of available channels and opportunities.

Rural camps and rural mini-camps which helped in the detection of mental retardation of thousands of children in various districts of Andhra Pradesh, also worked as an effective awareness creation as well as service initiation tool. These camps were devised out of the pressing urge to reach out with awareness programmes to the unreached rural communities. These camps were conducted incurring minimum costs, with basic reliance on local participation, convergence of services and resources. Local participation was generated towards making arrangements for the camp-site, providing of transportation for the patients for assessment, food packets for the camp participants, accommodation for the "Balasevikas" during the conduct of survey. Similarly the camp site was a fulcrum for the convergence of services from all concerned viz., local hospitals, local PHCs, PHC-sub centres, National Institutes / Local Specialists, Universities

and Welfare Organisations. Resources were available in the community but they had to be tapped properly to yield maximum benefits.

**v) Role Played at National and State Level:**

It was an NGO which rose to the need for a National Policy for the Mentally Handicapped, by mobilising the participation of policy makers, Government officials, reputed professionals, NGO representatives, representatives of different ministries and parents which resulted in an All India Seminar for Policy Formulation for the Mentally Handicapped in 1986. The policy document thus evolved was presented to the persons who were at the helm of affairs, responsible for its endorsement and enactment i.e., to then Prime Minister of India Mr. Rajiv Gandhi and the President, which resulted in the constitution of Behrul Islam Committee as a follow-up of its presentation. An exclusive working group was constituted under the 8th Plan for disability. Later due to various reasons the policy promulgation was unduly delayed. THPI's effort didn't cease at this level—this issue was vigorously and tirelessly followed up at all levels against various odds including change of Government till it culminated, in the passing of the “Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act -1995, the constitution of Rehabilitation Council of India to standardise the curriculum and to regulate the Rehabilitation courses, the increase in the allocation of budget from 40 lakhs to 120 crores in the current PLAN for the rehabilitation of disabled persons and so on. The various seminars, debates and workshops organised subsequently kept creating ripples in the ministry and vibrations across the country in different ways, the recent one being the implementation of the Disabled Persons Act of 1995. Various Ministries and Departments were on their toes to come out with concrete action plans. The National Trust proposed as an answer to “what after us” of parents, which awaits its enactment, has been one of the strong recommendations mooted by THPI at the Policy Seminar in 1987.

When the relationship between NGOs and Government was getting strained, and NGOs were accused by the Governments of misusing of grants and were treated as passive recipients of grants-in-aid from Government, it was THPI which rose to the occasion to sort out matters between the Government and NGOs by organising workshops at National and State level involving Government officials and NGO representatives from all over the country. These workshops were organised not because funds were available or support was forth-coming, but because of the burning commitment of THPI to the NGO - Government partnership which was the need of the hour. THPI drafted the report of a seminar in August, 1994, recommending major issues for a State Policy for rehabilitation of persons with disability.

**vi) Human Resource Development & Research:**

There is an acute shortage of professionals in the field of rehabilitation of the mentally handicapped at all levels. The brain drain of specialists continues, and rehabilitation of Mentally

Handicapped persons remains a field that is least attractive to professionals due to the strain and efforts called for. Considering the need and the pressing situations for trained professionals Thakur Hari Prasad Institute has evolved a need-based training modules and prepared the following personnel. Vocational training instructors, special education programmes for non-trained special teacher, grass-root level rehabilitation workers and supervisors and others.

It is because of the pressing need and requests from various NGOs for trained coordinators that Thakur Hari Prasad Institute embarked on a Post-Graduate Diploma in Developmental Rehabilitation and Diploma in Special Education (MR) to clear the backlog of untrained special teachers. In spite of various constraints THPI has not overlooked the need to develop adequate human resources. It started of with an ad hoc need-based crash programme before developing the training module into a Diploma Programme. Further, Thakur Hari Prasad Institute has pursued the Osmania University and Rehabilitation Council of India to recognise the Diploma to provide the course with a status and acceptance.

THPI has pressurised the NIMH to conduct a training programme for the members of State Councils for Child Welfare in the country towards the promotion of detection of children with mental handicap and their integration. THPI played an important role in organizing a seminar of Vice-Chancellors of Universities to ponder over the inclusion of disability as a subject at the graduation and higher levels of education.

It was again at the persistence of THPI that exposure to rural programmes got included in the curriculum of Diploma in Special Education (MR) so that the course participants could get adequately equipped. In-plan and in-built documentation of services and periodical evaluation of the regular services remains a part of THPI's regular activity. Apart from carrying out research on topics of current interest. The thrust has been to merge research as part of the action programme.

### **3. Concluding Remarks:**

This is the experience of an NGO which has journeyed beyond its set goals stretching itself to its maximum in utilising and creating every possible opportunity to develop awareness on mental handicap and educate the community about the rights of persons with mental handicap. There is no door that has not been knocked, there is no service model that has not been incorporated, there is no strategy that is left and untried, there is no area in which it has not ventured into, whether urban, rural or tribal, remote or peripheral. Various service systems evolved by THPI serve as role models to National Institutes in its multidisciplinary approach in rehabilitation, awareness building strategies, such as rural camps, media seminars, community level intervention strategies etc.

THPI has extended itself to shoulder bigger commitments and responsibilities starting from the preparation of policy documents to lobbying for its enactment as a legislation with

the support of other NGOs, sensitizing the policy makers, educating professionals, family members and the community. Overcoming the barriers of the present socio-economic political system THPI has proved that it is possible to facilitate empowerment of persons with mental handicap to live a life with dignity in society. In doing so it had to weather many obstacles including acute shortage of all kinds of resources. But the THPI dictum stands "Rain or sunshine, money or no money the work will go on". And yes, it has made it! And it was possible only because it had a clear VISION and MISSION supported by a team committed to its realisation.

Through its very unique contributions THPI has therefore raised the status of NGOs and elevated the role of voluntary social action through professionalisation and commitment to quality of service to higher levels. THPI is set to expand its horizons to play still bigger roles as partners in the habilitation of persons with Mental Handicap. If this is possible for one NGO just anyone can do it provided there is a singular dedication to the cause and quality of service, sensitivity to the target group and the socio-economic context as well as determination to achieve its goals.

Voluntary social action can never be suppressed nor can it be extinguished. Its powers are unlimited. And in developing countries like India with its socio-economic problems and scarce resources, only an NGO action in partnership with Governmental action can ensure the rights of persons with Mental Handicap for equalisation of service and opportunities.

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# Role of Voluntary Agencies for Prevention of Mental Retardation and Mental Illness through CPR Approach

## **Introduction:**

As rightly said 'PREVENTION IS BETTER THAN CURE' and the cost of prevention is much lower than the heavy investment on treatment and rehabilitation after the problem has occurred. Health care sector is entrusted with the primary task of providing 'Health for all by 2000 A.D.' It means absence of health problems, mental illness and disabilities such as mental retardation. Therefore prevention of the major disabling situations such as mental retardation and psychiatric illness as priority problems to be tackled should form an integral part of the health care system. This would not only lead to an effective and optimal functioning of the health sector but also solve one of the age old and ever increasing problems such as inadequate facilities, acute shortage of resources, unwillingness of professionals to work in rural areas and so on. It is in this context, that the Ministry of Health was pressed with the urgency to bring out a strategic plan of action for integrating prevention of Mental illness and Mental Retardation into the existing health systems PHC in this case as a mainstream programme. These two problems are focused as the prevalence rate shows that they are present in large numbers causing "distress" and "burden" to the families, communities and nation. People's participation as vital to the successful implementation of such a strategy has been duly acknowledged. Hence the seminar intends to develop a model system with minimum infrastructure using existing Primary Health Centres (PHC) on the principles and approaches of Community Participative Rehabilitation (CPR).

To make it happen, that is integrating prevention of mental retardation and mental illness into the health system, we need to have a policy without which disability prevention will continue to receive the "least prioritized attention" by the health and other sectors. Moreover, programmes that do not clearly fall within the mandate of the health care system, are those that are most vulnerable for discontinuation at the hands of cost restraint efforts. Experiences have also shown that often health infrastructure by itself fails to yield expected results in

the prevention of disability and this additional task is viewed as an imposed burden very often.

There was also overwhelming experiential evidences to prove that some of the factors that account for the SUCCESS of such programmes at community level are:

- Making programmes community based
- Close supervision and effective monitoring by NGOs
- Flexibility of the projects to adapt to the local needs and context.

Therefore, it was realised that PHC and other such traditional systems will not work without a certain level of local responsiveness to external organisation or monitoring. It is in this context that the need for involving NGOs becomes crucial. We need to delineate the specific roles they can play, and the kind of support they require for facilitating effective implementation of the proposed national programme. We need to develop clear guidelines for the implementation of this approach.

In suggesting such a direction, we are mindful that there is no one “right” solution or set of programmes for any particular region. The policy would provide provision to incorporate sufficient flexibility to meet challenging needs both across and within communities. CPR programmes represent a wide range of options within which choices for service delivery may be made. Besides, policy, there is a need for a Centre for information exchange, possible coordination and periodical evaluation a Centre that will not function as a power centre or decision making apparatus, but rather as a facilitator and means to ensure that we continue to benefit fully from exchange of knowledge, experience, success, failures, and suitability of the project. We also need to set a criteria and evolve evaluation tools to ensure the proper implementation of the proposed model.

A question may be asked as to why confine to “Mental Retardation” and “Mental Illness” alone. Does it not deviate from the commitment and philosophy of CPR towards integrated approaches? This is a onetime effort to specifically look into the needs of these groups so that these specific needs would not be neglected in the mainstream programmes as is often the case (for e.g. in DRC programme, MR gets the lowest priority). We also acknowledge the fact that the causal factors are common for most of the disabilities and at times there are multiple causative factors for one disability requiring inter sectorial approaches. But what we are concerned about is to make a conscious exercise specific to the prevention of Mental Retardation so that more relevant aspects pertinent to any of these disabilities gets overlooked or missed.

Another subtle but very significant factor that has to be taken note of is that MR has always been confused with MI and there has been a continuous effort to separate these

two as Mental Illness is a disease that can be treated with medicines whereas, mental retardation is a condition that can be improved only with regular training. The issues pertaining to these two aspects have come to a common platform for discussion. While discussing common approaches for integrating prevention services of MI and MR with PHC we need to treat them as separate entities.

*The present seminar intends to look at...*

1. The various components of prevention that we need to address to
2. Analyse and review the existing status of CPR in the implementation of preventive services for MR and MI and the role of NGOs.
3. Evolve a viable model for integrating preventive strategies of MR and MI as a national strategy through CPR approach.
4. To formulate a policy for the launching of this national strategy towards the prevention of MR and MI.

*With this purpose in mind:*

An attempt is made to briefly touch upon the prevention we are addressing to today, CPR as understood by us and provide an overview of the CPR programmes implemented in our country. An attempt is also made to focus on the issues that we need to address ourselves in the light of the above.

### **1.1 Mental Retardation and Mental Illness:**

We are addressing ourselves to two major issues viz. prevention of mental retardation and mental illness. Mental Retardation refers to significantly subaverage general intellectual functioning, resulting in or associated with concurrent impairments in adaptive behaviour, and manifested during the developmental period.

As per WHO International Classification of Diseases, mental retardation has been classified as under.

I.Q.	50	-	70	Mild MR
"	49	-	35	Moderate MR
"	34	-	20	Severe MR
"	19 &	-	<	Profound MR

The prevalence of MR as per the available estimate is 2 to 3 per cent. Services available are grossly inadequate. Services are almost nonexistent in rural areas as available services

are concentrated in the urban areas. Misconceptions, false beliefs and practices accentuate the problem.

## **1.2 Mental Disorders:**

WHO experts have reported a prevalence of 13.9% of psychiatric morbidity in the general population. It is also estimated that 15-20 persons visiting PHC or general practitioner have in fact emotional problems which appear as physical symptoms. Health has been defined not as merely absence of ill health, but as a state of positive well-being, physical, mental and social. Mental health therefore forms an essential part of total health as such and must form an integral part of the health policy.

*The various mental disorders are:*

1. Acute mental disorders of varying etiology, like acute psychosis (which can become chronic if not detected and treated in time).
2. Chronic mental illness such as schizophrenia, affective psychosis, epileptic psychosis etc.
3. Emotional illness such as anxiety, hysteria, neurotic depression.
4. Alcohol abuse and drug intake (These areas will be dealt with in greater details)

## **2. Preventive Measures that we are Addressing:**

Prevention is narrowly defined as inhibiting the development of a disorder before it occurs. Broadly defined, prevention includes measures or interventions that interrupt or slow the progression of a disorder. Thus, different levels of prevention exist.

In this model primary prevention relates to measures taken to eliminate or reduce diseases, genetic or environmental factors that damage a developing organ or system. These measures may be general (that is, they may prevent several conditions) or specific, (e.g. polio immunisation). They may also be educational.

The expanded programme of Immunisation is a special effort on the part of UNICEF to improve the general health of children, while at the same time preventing specific impairments resulting from whooping cough, diphtheria, and poliomyelitis. Promotion of oral rehydration therapy and the education of health workers in its use is another example of a general preventative health measures which may prevent some disabilities. These strategies should be integrated into health care programmes and in health education in schools. Good post-natal care can also be regarded as a most important prevention programme which can significantly reduce the impact of maternal conditions during pregnancy on the developing foetus.

Secondary prevention has the prevention of impairment as its target. The agent has already attacked the individual but it has been identified early and measures are taken to reduce the damage. Adequate neo-natal care for the premature baby, the treatment of babies with PKU with a phenylalanine-free diet, and early and effective treatment of meningitis are all examples. This involves preventive and curative health measures and effective public education to improve the use of health services.

We should also bear in mind the multiple risk factor model as handicap in children are typically due to multiple causes which are manifested through developmental delays. Psycho-social retardation, for example, has high prevalence among urban-minority, and low income groups. There are many seemingly normal births in this population where there are previous subclinical neurological conditions (associated with malnutrition, for example), which when associated with poor environmental stimulation lead to subnormal intellectual performance. Such combinations of causes are likely to be much more deleterious. Psycho-social causes of handicaps are a complex set of etiologies which include biological factors if they are to be fully understood. This type of multiple-agent conceptualization is required as the predominant theoretical basis of a prevention model.

A very recent study reveals that model interventions to improve the developmental outcome, of Low Birth Weight infants did not cause a reduction in the rate of mental retardation in the population after a 24 year trial period. In contrast reducing the proportion of children living in poverty who are exposed to environmental deprivation significantly decrease (10%) mental retardation at the end of the model's time period.

This study reveals that long-term reduction in the prevalence of Mental Retardation is attainable by modifying public policies that influence children's developmental programmes.

While in principle there is a considerable information to suggest the appropriateness of a multiple causation model, we still do not have any longitudinal systematic tracking data beginning in infancy and extending through school years. Hence, the relative contribution of social, medical and environmental risk factors as causes of particular categorical handicaps remain theoretical. For our discussion the possible preventive causes can be named as the following.

## **2.1 Causes of Mental Retardation can be Categorised as:**

1. Causes occurring before birth, Genetic & Non-genetic
2. Causes occurring during birth
3. Causes occurring after birth

### 2.1.1 Before Birth:

- i) **Non-Genetic:** Infections such as German Measles. Sexually transmitted diseases such as syphilis, HIV, fits, drugs, alcohol consumption, smoking etc.
- ii) **Genetic factors:** Chromosomal disorders (Down Syndrome) which accounts for 30% of severe mental retardation, fragile-X syndrome with an estimated incidence of 1:2000. In addition, there are other known disorders with abnormalities of the number of structure of chromosome (1% - 4%) and the inborn errors of metabolism. A summation of these causes leads to the conclusion that more than 50% of severe mental retardation is genetically determined. Tests are available to detect any of these problems
- iii) **Other risks before pregnancy:** Anaemia, kidney diseases, diabetics, mellitus, high B.P., poor nutrition are some risk factors which warrant periodical check-up and care. If the age of the mother is less than 13 or more than 35 years can also cause complications. Other risk factors are history of miscarriages, still births, inherited conditions etc.

### 2.1.2 During Birth:

Problems such as prolonged and difficult labour premature birth, birth asphyxia are responsible for 10 - 20% of cases becoming mentally retarded later. Mothers should be advised against drugs, alcohol, cigarettes etc., during pregnancy. Emotional trauma should also be avoided as it is a risk factor. Exposure to X-ray, pesticides etc. must also be avoided.

### 2.1.3 After Birth:

Accidents leading to head injury, infections of brain like meningitis and encephalitis, untreated fits, fusion of sutures of skull, recurring lowering of blood sugar levels and chronic lead poisoning are factors that can damage the growing brain leading to mental retardation.

Treatment for Rh incompatibility and PKU/Hypothyroidism will prevent retardation. The child should also be protected against environmental deprivation with proper care and adequate food and in an environment love, care and healthy interaction.

The most important message is that treatment is available to prevent most of these incidents. Almost all these programmes are available and accessible barring genetic tests. What is required is we have to sensitize the health functionaries, and disseminate information at all levels. We need to COMMUNICATE at all levels. In the light of rapid advances in the field of genetics, today we can diagnose with certainty the genetic risk involved and parents at risk can make informed decisions.

## 2.2 Secondary Prevention:

Once the child is born retarded the immediate task is early detection and intervention. Many simple screening tools are available that helps one identify mental retardation on the basis of delays in normal milestones of development. It is easier to find out children with moderate, severe and profound retardation because of obvious gross delay in the development. Sensitive tools can screen out children with mild delays.

Early detection and correct diagnosis is most important for providing timely early stimulation. As we all know the chances of optimal improvement is very high during the first few months / years of the baby when there is a plasticity of the brain which can help overcome the functions of some of the lost cells.

Training needs to be imparted on early detection to all health personnel. Early stimulation can also be taught to parents by these functionaries.

With regard to early stimulation we have various models such as the well know head start programme of the West started in the early 1960's, portage programme and many other innovative methods adopted by the NGOs. What needs to be conveyed is that we have the technical acumen of prevention, but what is required is mass scale and effective implementation of the same. Certain issues merit discussion at this point.

- a) Most of the early stimulation programmes especially portage relies heavily on home-based training as it should in terms of empowering the parents and proper utilisation of the "most potential" human power available. But various experiences have shown that at times it becomes difficult for a poor illiterate mother in a poverty stricken nuclear family to carry on home-based training and stimulation programme as both parents have to struggle for their survival needs all day long having very little time or energy to attend to home-based training. It is in this context the support of a peripatetic trainer and or a 'neighbourhood centre' for day care that needs to be realistically looked into.
- b) While most of the preventive tasks can well be carried out by the existing health staff, we need to have separate personnel at grassroot level to attend to early stimulation programmes of the mentally retarded children. Developing ANMs and other local functionaries and in their absence separate personnel need to be available for it (where the NGOs role comes in a big way).
- c) Rich resources and effective traditional methods already exist in many rural communities. What is required is to put them to a more conscious use. Special focus may be given to the interaction between mother and child. The skills of baby massage handed down from generations of Indian women are some examples. No one teaches the skills which are appropriate for early intervention. Intervention will be effective and sustainable

by using the existing traditional methods. Acceptance and assimilation will also be quicker. This is another area where NGOs can make a considerable contribution.

### **2.3 Superstitions Beliefs and Misconceptions:**

While we concentrate on the components of prevention, strategies and the messages to be conveyed we have to bear in mind the various wrong notions prevailing in each region about preventive methods. For e.g. in some places women are prevented from eating leafy vegetable during pregnancy. There is resistance from the community towards immunisation. Many harmful practices such as putting hot iron rod on some parts of the body to cure internal problems. These issues need to be dealt with carefully on the basis of the prevailing local beliefs, customs and practices.

### **3. WHAT IS CPR:**

Having addressed ourselves to prevention, we need to clarify our prevention channels, that is routing programmes through existing health infrastructure. In this context a look at the concept of CPR becomes inevitable. Our task is not to go into the much-debated and known issue of WHY CPR and its SCOPE but just to understanding WHAT CPR means and what it implies in the field of prevention in order to facilitate discussion and plan of action.

The concept which has been clearly defined by the WHO committee as: 'Community Participative Rehabilitation, which involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped persons themselves, their families, and their community as a whole'. Neither this statement nor other WHO formulations make clear what is understood by 'the community level'. Does it mean 'Community life', the 'Resources of the community', or the 'Community as a whole'.

However, from the WHO manual we can discern that CPR envisages activities taking place within the home of the disabled person, and integrative action being implemented at community levels e.g. day care centres, schools, youth clubs, community centers etc. One thing is clear that CPR takes a turn from the traditional institution based rehabilitation to one based at the community level.

*The concept of CPR means:*

- Awareness and concern of the community
- Initiatives from the community
- Planning by the community
- Resources of the community

- Implementation by the community
- Evaluation by the community
- Modifications by the community

### **Scope of CPR:**

*From the various CPR programmes implemented so far the scope of CPR includes:*

- Prevention of disabilities
- Identification of high risk mothers and infants
- Early detection of disabilities and management
- Assessment of the needs of the disabled and the family
- Home-based or 'neighbourhood' centre based programme
- Parental involvement
- Play groups and integrated schooling for children
- Advocacy groups and parent support groups
- Organisations of disabled people and for disabled people
- Equality and equalisation of services
- Solidarity
- Social Integration

A look at the scope of CPR as evident through various projects tells us that more can be achieved by the disabled through CPR than through institutionalised rehabilitation.

### **3.1 Community Participation:**

Community participation is the key to CPR programmes may be explained as a process in which people become more aware of their rights and their problems and understand how they themselves can be involved and contribute to the health and also their strength and resources. There are three major ways in which a community participates.

1. Community can provide facilities, manpower, logistic support and possibly funds to the services.
2. The community can be actively involved in studying its problems, decide upon feasible solutions and implement them.

3. Participate in primary health care services (for preventive and protective measures).

The Alma Atta declaration states that essential health care is based on APPROPRIATE and ACCEPTABLE methods and TECHNOLOGY made universally ACCESSIBLE to individuals and families in the community through THEIR FULL PARTICIPATION and at a cost that the COMMUNITY and country can afford to maintain the spirit of self-reliance.

*It implies*

- Demystification of Technology
- Mass Transfer of Knowledge
- Human Resource Development
- Encouraging Community Participation
- Routing programmes in the community through convergence of services and effective networking.

The three major components viz. Demystification of technology and mass transfer of knowledge, human resource development, (personnel development) and community-based approaches are further elaborated as follows:

### **3.1.1 Mass Transfer of knowledge:**

Demystification of knowledge that makes technical knowledge simple, understandable and available to laypersons, empowering the family members, volunteers, and community at large with the knowledge of the causative and risk factors of mental retardation and mental illness, simple low cost preventive measures available in the community and guide them in the utilisation of the same. Knowledge has to be communicated to...

- a) Young prospective parents, pregnant mother,
- b) Grand parents and important family members who influence the decision making process,
- c) Opinion builders in the community such as religious leaders, village leaders teachers etc.
- d) Other functionaries in the community like local doctors, dais, ANMs etc.)

While the existing village level workers can impart essential knowledge to the family members on these preventive aspects. Early detection and essential interventions for the mentally retarded, they need to be Reinforced by other community forces. The message needs to be communicated in an effective and psychologically acceptable manner too.

NGOs working in the field have evolved various innovative, locally relevant awareness building strategies such as folk stories, folk songs, street plays, films, audio visuals, pictorial presentations, public campaigns, word of mouth campaigns, small group discussions and so on. This is an area where the NGOs can serve as effective agents of awareness building.

### 3.1.2 Human Resource Development Training:

Training needs to be repeatedly stressed as it is basic to the implementation of CPR programmes. The present programmes envisages different categories of personnels and para-professionals.

- a) PHC level - PHC Doctor, multipurpose health workers, village level health worker, auxiliary nurse-cum-midwives
- b) Village level workers who will be entrusted with this task by NGOs.
- c) Key NGO functionaries
- d) Rehabilitation professionals

*The major components of training are:*

1. Possible causes of Mental Retardation and Mental Illness
2. Preventive measures
3. Facilities available (what and where)

*Knowledge related to these needs to be imparted depending on WHO is to do WHAT. Therefore we need to specify.*

1. The type of personnel who is going to be involved
2. Role of each category of professionals
3. Type, nature and duration of training programme for each category.

With regard to the grass root level workers who need to be introduced into this programme by NGOs, we need to specify their educational background, sex, previous experience etc. We suggest that preference be given to those who are already working in the field or have some exposure, SSC or in the absence of which minimum assimilation capacity. Females are preferred as a strange 'male member' may not be accepted in traditional families for regular visits and guidance. These issues need to be further debated and discussed. In cases NGOs already have well trained and experienced grassroot level workers such as balwadi teachers, peripatetic teachers etc. Hence stock taking of the existing resources also needs to be done.

### **3.1.3. Community - Participative Approaches:**

Routing programmes through the community and with the community is the major focus and thrust of the CPR programmes. There is no set model or strategy for this. There are numerous ways by which it can be done and NGOs have proven their competence in building-up self-sustaining CPR projects. The various strategies can be studied and listed out so that one can choose what is locally relevant and viable (local community groups, 'sangham model' of Action aid, three tier model of THPI, parents self-help groups etc.) An overview of some of the CPR programmes will be of help in this context.

### **3.2 Overview of CPR Projects:**

Projects have been implemented both by the Government and NGOs in different parts of the country in response to the growing needs of the problems of disability in the rural areas. The last one-and-half decade has witnessed various attempts in the field of rehabilitation with the Government emphasizing the concept of equalisation of opportunities and human rights for disabled persons and as a result of the voluntary initiatives of NGOs . A review of these projects help us to sketch out certain major approaches.

Programmes that are promoted by coordinating the delivery of rehabilitation resources to rural communities (THPI model, Hyderabad)

- i) Institution-based extension services (NIMH Model)
- iii) Community-Based Programmes (Action Aid, - THPI model, Lalacheruvu)
- iv) PHC - based or hospital based programmes (DRC "Early Intervention with Infants At Risk" implemented by APACWMR)

### **3.3 Impact of Government Programme:**

In 1985, the GOI decided to implement CPR projects on a pilot basis for the rural areas. The objective of the pilot project was to develop a cost effective model that could be sustained by the Govt. and the community necessitating its integration at the community / grassroot levels with different departments and the NGOs working in the field of rehabilitation. This model, not only has rehabilitation as its objective but also emphasized prevention and early detection. The model was comprehensive in nature and aimed at the rehabilitation of all disabilities in all age groups. It aimed at promotion of voluntary efforts and conducting research, so that aids and appliances could be adapted for rural conditions.

It also aimed at being very cost-effective. GOI has set-up initially 6 and later 6 more were added. After 4 years the project was evaluated. Evaluation showed that in general DRC had made considerable impact and there were many areas of deficiencies that could be improved

upon. One major deficiency that shackled itself as an other bureaucratic structure failing in effective coordination, in involving the community, and in networking with available resources.

A revised plan is being drawn up on the basis of the recommendations of the evaluation report which is expected to be the National Programme on CPR Services, covering the entire country. We may consider the possibilities of promoting NGOs to run some of these projects in view of their proven ability to involve the community.

### **3.4 CPR by NGOs:**

Efforts of NGOs toward CPR are evident since 1980 as a spontaneous response to the problems of rural communities. A few NGOs have done outstanding work in terms of running CPR programmes for the prevention of disability. (A few of them are, the CPR programme run by THPI, Hyderabad, Seva-in-action, Bangalore, Samadhan, New Delhi, some UNICEF funded projects, Action Aid, Bangalore etc.) one of the pioneering institutions to go in for CPR was THPI. It may also be noted that THPI was the first and unique of its kind to initiate a Rural Community Participative Rehabilitation Centre for the Mentally Retarded in Lalacheruvu of Rajahmundry Dist.

The THPI model at Hyderabad has adopted a three tier system, with THPI functioning as a consultative team with thrust on "bottom to top" implementation. An existing infrastructure in the community, the local 'Balwadi' served as the local centre for regular monitoring and local balwadi teachers and 10 volunteers (including a few mothers) functioned as the village level catalysts. Regular supervision was provided by a village supervisor in the ratio of 1:10. The team provided consultative support and referral service. The success of the project has to be judged from the fact that the project initiated in 10 villages spread to other 10 villages with no additional funding. The project continues 5 years after the withdrawal of UNICEF support. The coverage has expanded, and programmes have multiplied, with speaks of the success and sustainability of the extended community based approach. Use of indigenous training aids, awareness building, informed decision making are some of the highlights.

The model is marked for its net working with local agencies such as PHCs, local schools, hospitals, youth clubs, family welfare centre. This model shows that CPR does not stand alone. CPR is one segment of a comprehensive approach to rehabilitation in which the Government, NGOs and the community all play complementary roles.

There are many examples of different approaches to CPR. There is no single model of CPR as each project must be based on local facilities and the developed service should be compatible with local customs, culture and priorities. There was also diversity in terms of target groups covered, duration of the project, (as many project were wound up after 3 to 5 years, external support), methodology used, philosophy of running the project etc. This makes even evaluation of projects difficult.

Nevertheless we need to evolve certain criteria for inbuilt monitoring and evaluation so that the findings can be widely shared. At present most reports are simply descriptive and although of intrinsic help they do not help us to judge the efficacy of the programmes.

On the basis of an extensive review of the various projects launched by UNICEF it was noted that NGOs and funding agencies have tended to have a project bound approach in which the implementing agency "does CPR" of the, inadvertently leading to dependency on the outside agent which is, in fact, the opposite of what has been aimed at.

A recent report of UNICEF on the basis of its evaluation of 40 projects supported by it, while appreciating the innovativeness and commitment of NGO's has raised a few concerns relating to CPR approach.

- The NGO projects tend to remain as pilot projects covering limited population with no facility or planning for expanding coverage or reaching wider geographic areas.
- The NGOs which receive funds from UNICEF for a limited period tend to depend solely on UNICEF funds resulting in inability to continue the project beyond the period supported by UNICEF.
- Monitoring of these projects is generally weak and documentation of innovative strategies and the process in particular is poor.
- NGOs involved in implementing innovative projects tend to operate and function in isolation with regard to other child-related and welfare projects especially those implemented or supported by the government or local bodies.
- The tendency of the majority of the NGO's is to focus on higher age group and not the 0 - 6 years age group.
- While it is universally accepted that the most effective way for implementing interventions on childhood disability are in conjunction with the primary health care infrastructure, this actually happens very rarely if at all.
- That where there are several NGOs in particular locality / geographic area operating programmes relating to childhood disability there is no effective collaboration or cooperation. This leads to at times duplication of activities and overlapping in coverage.
- The NGOs tend to operate in areas where there is already ready cooperation and community support. As a result in the backward areas where the problem may be severe and the need acute, there are no NGOs to undertake interventions for the population of such areas.
- NGOs do not seem to be too enthusiastic to participate in any government programme,

e.g. District Rehabilitation Centre scheme where the Ministry of Welfare, Govt. of India has made specific provisions for support to NGOs who are willing to be involved in the implementation of the DRC activities. UNICEF assistance has also been offered to NGOs who are willing to undertake activities relating to awareness creation and parent counselling.

Nevertheless the success of NGOs in the effective conduct of CPR programmes outshines the lapses and disadvantages. Their role has been acknowledged at all levels along with the realization that Govt. cannot be successful unless they join hands with NGOs in the running of CPR programme. The debate is not whether to have them or not, but how of specific cooperation.

#### **4. Identification of NGOs.**

What is required is proper identification of those NGOs who have made a major contribution in this field, and have enough expertise and experience. The last one decade has seen the mushrooming of hundreds of NGOs working in the field with programmes which have a poor impact due to wavering degrees of commitment and purpose. Hence we have to be CAUTIOUS in the selection of NGOs who are going to be entrusted with national programmes and certain criteria needs to be set for the same.

*The myriad roles NGOs can play can be summed up as:*

1. Coordinating with the PHC for the implementation of preventive programmes on MR & MI
2. Developing innovative awareness building materials and methods
3. Support for human resource development (existing manuals, training materials, resource persons)
4. Effective referral services
5. Camp approaches for early identification of MR and MI
6. Community networking with other resources, personnel and organisations
7. Research
8. Raising funds from Governmental sources
9. Policy development

## *Policies*

# Using Communication Media for Public Awareness

## 1. INTRODUCTION:

The potency of the media in reaching people with information is an indisputable fact. While news papers, books, magazines, T.V., All India Radio exert a uniquely powerful influence in enabling literate and urban people to understand the WORLD AROUND THEM, many other forms of “local media” exert influence on the illiterate, poor innocent and ignorant people in remote rural and tribal areas who form a significant proportion of a developing country like India. Today, we are also well aware that there are numerous ways and endless number of media format by which information can be transmitted to people. But we must also realise that little effort has been made to “reach out” to people through these communication media in the field of rehabilitation of disabled persons.

The present paper intends to share the successful experiences of an NGO in reaching out through multifaceted multi-pronged media approach. The intention is not just projecting “what has been done”, but to effectively share experiences that work in the field of rehabilitation, and REPLICATE strategies in the effective and optimum utilisation of communication media in the field of rehabilitation at various levels. Yes media can do wonders in the field of rehabilitation provided, we are committed to it and determined to make use of it.

The present paper discusses briefly how different media have been effectively used in reaching the main target groups who are to be addressed — parents and family members, opinion builders in the community and other professionals, rehabilitation professionals, media-professionals and policy makers. Major issues such as early intervention, prevention, rehabilitation, employment, equal rights etc., have been addressed through the use of same media in different forms or different media to meet these different target groups. The result is very encouraging demonstrating the multifaceted and indispensable role media can play in the rehabilitation of people with mental handicap. Experiences advocate for media-based rehabilitation to realistically respond to the needs of millions of mentally handicapped persons specially and disabled persons in general in developing countries.

## 2. The Scenario :

India is a large country with the population touching almost 900 million with its concomitant problems such as poverty, ill health, unemployment, illiteracy and ignorance. Available estimates

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show that around 10 per cent of the population is affected with one disability or other and around 2 to 3 percent are mentally retarded. The existing services provided both by Government and NGOs put together hardly caters to 2% of the needy though there is a growing awareness of the issue and also many efforts to attend to their training needs and so on. There is an acute shortage of manpower, resources and finance. Existing service are concentrate in the urban areas which constitute around 30 per cent of the population, leaving the rest unreached. Around 50 per cent still live below the poverty line and around 52 per cent of the population is, illiterate. Superstitious beliefs, ignorance, misconceptions dominate and rule. Millions have not been reached the need of the day is to EMPOWER people with knowledge and skills; sensitize politicians and policy makers for due support; motivate and prepare professionals. The focus remains EDUCATION, SENSITIZATION, HUMANISATION and PROFESSIONALISATION through MASS TRANSFER OF INFORMATION, the required information and services. Ignorance prevails at all levels viz. parents, community, professionals, planners and policy makers. A great deal has to be done for people with mental handicap for them to lead and enjoy a better quality of life.

### **3. Sensitising Direct Target Group :**

*(Parents, Family Members, Persons with Mental Handicap)*

Issues focussed on are:

- Prevention
- Early detection, intervention and integration
- Nature of Mental Handicap
- Training needs, service facilities, social benefits etc.
- Contributory role of persons with mental handicap and other disabilities
- 'Misconceptions' and 'Wrong practices' and 'Negative images'
- Role of Parents and family members  
(Small ways in which they can help).

Awareness and attitudinal change have been brought about in thousands of family members through the approaches mentioned below.

#### **3.1 Rural Camps :**

This strategy is used in identifying people with mental handicap in the rural areas and guiding them regarding rehabilitation procedures through camps conducted by the multidisciplinary professionals at the village level.

A few comments of parents speak for themselves on the impact of these camps. One mother speaks:

“You have opened our eyes, after years of wasting our time, energy and hard earned money on consulting local healers and doctors....”

Another old father broke into tears

“....Madam, today we understand what the problem with my son is....I was waiting for him to speak and become normal.....”.

“Now we know how to help my daughter and.....” Rural camp for many hundreds of parents have been conducted for the FIRST TIME, they were told about what mental handicap is and what could be done. “Madam, we thought he is ‘pagal’ (mentally ill) and tied him in our house, beat him when he misbehaved..... no body told us what can be done to help him.....”

Some of the false beliefs that existed in these places that could be stumbling blocks in rehabilitation are:

“That a Mentally Retarded child was born because of past sins.....”

“Born as M.R. because the mother ate papaya when she was pregnant”

“A Mentally Retarded child is a gift of God and needs to be worshipped”

“A Mentally Retarded child is a possessed by a ghost and the ghost must be driven out through thrashing, starving and puritive punishments”.

“Mental Retardation can be cured by getting the person married off”.

It is extremely difficult to wipe out age-old beliefs and traditions overnight. But a well planned Rural camp did dispel these beliefs in many families. The change was visibly seen on their faces and in their expressions and in their active participation in training programmes. Apart from this community participation was elicited in the conduct of the camp - such as involving local Panchayat, Mandals, local opinion builders, general practitioners, hospitals, Public Health Centres and Dispensaries. Their participation in variety of ways such as providing camp site, materials like, shamiana, tables and chairs, food and water for camp beneficiaries and so on - resulted in the much needed awareness among these community members too! At a few places, the leaders came forward to donate sites and building requesting us to start a rehabilitation centre.

### **3.2. Other Awareness Building Materials :**

Other materials that supported this awareness building mission was, door-to-door survey, pamphlets, exhibition, announcements about camp going about in auto-rickshaws, ‘dandora’

(a drum beat popular in villages in announcing about programmes) street plays and songs. The message is that a combination of various media was used to bring out a tremendous awareness building, attitudinal change and motivation to initiate rehabilitation training. These media not only helped in developing awareness among the family members but also among the community leaders and others. These camps enabled to address many issues. Apart from building awareness, it also enabled to motivate people to action.

Some of the other strategies that were used for these target groups were group discussions, talks by professionals, films and supportive guidance by Public Health Centre workers in spreading information on prevention. Where Public Health Centre was absent, local teachers were used as “Communicators”.

#### **4. Awareness through Action Programmes :**

Seeing is believing. Thakur Hari Prasad Institute was fortunate to have made an ENTRY into nearly 400 villages of Andhra Pradesh through its sister organizations that run “balwadis” (Pre-schools). The balwadi teachers were trained to function as catalysts in early detection, early intervention and early integration of children. When this integration of children was first introduced some parents resisted.

- One parent said “Why mix these pagal children with normal children in the balwadis? Our children will also become pagal”

The responses of parents of disabled children weren't positive either; some of the responses were:

- “Well, God had given us this ‘species’. We will feed him as long as he is alive and let him live in the house.”
- “Madam, what can Balwadi do for this ‘Pagal’? Can you make him normal. No. Why should we waste our efforts and send him to Balwadi. You leave us alone.....”.

But the fact is our ‘Balwadi teachers’ didn't give up. They worked with perseverance and commitment. Today “integration” is the talk of the town, a well accepted programme in the village. Some of the disabled children were mainstreamed into the local primary schools and follow-up was taken-up when required.

Training programmes were conducted for teacher from normal schools on integrated education which resulted in their ACCEPTANCE and implementation of the programme. Today other Mandals have approached Thakur Hari Prasad Institute to carry out similar training programmes in their Mandals too which have been taken up in a phased manner. The end result is that around 1500 disabled children benefitted through this integration programme in these rural areas, and hundreds of teachers were sensitized.

The same acceptance was created in the urban area by a unit catering to the full integration of pre-schoolers, and through wide-spread neighbourhood social integration programme. The programme though initially met with resistance from teachers with pleas for non-distance of their teaching atmosphere. Today we find acceptance!. Today these teachers are advocates of integration, serving as communicators. Media that was used was made of short training programmes, exposure to Mentally Retarded children, actual experience of integration programme and professionals support when required.

#### **4.1 Integration Camps at National and International Levels:**

The camps organised by the Institute in collaboration with other organizations in integrating children with mental handicap with normal peers resulted in effective awareness building among hundreds of normal peers in the country and across the country (who would have not got the opportunity otherwise) and grown with negative images and misconceptions about them. Awareness and positive images have been built among adults who participated as care-takers too. The report of these programmes were eye openers to the organizers and sponsors who welcomed these initiatives and promised support for continuity and promotional activities.

#### **5. People with Disabilities as Effective Communicators :**

No other media can be as effective and as powerful as people with disabilities as COMMUNICATORS. The visible progress that can be noticed in people with mental handicap is communication with family members, community and professionals (both rehabilitation and other - because it is the experiential belief of a rehabilitation professional that enables him to form realistic opinions) about the impact of training, need for training and abilities of people with Mentally Handicapped as contributing members of society.

The different cultural performances organized by Thakur Hari Prasad Institute at various functions at National and International levels and as part of fund-raising campaigns created an indelible impact amongst a heterogeneous audience regarding the innate talents and abilities of people with mental handicap. It has also driven home the message that with proper training, they can perform at par with any normal person in any given field.

Today our institute has placed around 50 adults on supportive employment in Printing Press, Bakery, Stationary shops, Super Markets, Welding works and so on and around 200 adults in various local jobs such as Carpentry, Weaving, Laundry, Farming, Frazing animals, House hold activities, Small-scale industries and so on in rural areas. These people have proved beyond doubt that they CAN WORK, EARN and CONTRIBUTE. Today a few of them support their aged parents who were overwhelmed beyond measure as they thought these persons could never be of help to others and were burden to others. The employers who have hired their services are fully CONVINCED and need no more evidence about their capabilities instead they act as spokespersons and motivators to other employers.

These employees with mental handicap speak for themselves with a SMILE on their faces about their work, the new found joy in earning and contributing just like anyone else.

Parents who have been involved in home-based programmes and who have experienced and seen the change in their handicapped children have also become effective communicators. They helped in motivating, supporting and training many other parents in these as well as neighbouring villages! They are key personnel in WORD OF MOUTH CANVASSING.

## **6. Convergence of Existing Media :**

We do not have a universal plan for improving accessibility and distribution of appropriate information to the target group. Though such a system is desirable and needed it may not be possible in the near future. We have made use of the existing channels in the community - viz., health infrastructure (Primary Health Centres and Sub-Centre), Integrated Child Development Programmes, Pre-School structures etc., to promote knowledge on disability and rehabilitation skills. Home-based training and use of low cost, locally available materials were effectively communicated through audio-visual aids. These benefits are considerably expensive. These materials can be duplicated than, the training programmes and hiring of therapists from specialized institutions. This is not to say that direct training Programme can be replaced or substituted by media (indigenous and others) or to dispute the efficacy of one over the other but to suggest workable alternatives. Where we can afford, media-information supported by training programmes was found to be of immense value.

## **7. Awareness Building among Media Professionals :**

A series of 3 media seminars conducted at 3 different metropolitan cities of India has created sensitisation among both print and electronic media. Today Doordarshan telecasts 'messages' about mental handicap at prime time. The press takes press notes seriously and make it a point to give coverage on any programmes on disability.

The Institute file today swells with these press cuttings. The press includes the programmes in engagement columns too. Professionals are invited for radio-talks on disability. Recently there was a serial built round a 'Mentally handicapped person and his family' on Doordarshan telecasted at prime time. Doordarshan has approached our Institute for support in developing various materials which have been willingly extended.

These are welcome changes but are not enough and the responses are not uniform. There needs to be a media policy for implementation at the national level.

## **8. Awareness Amongst other Professionals :**

The role of other professionals in the communities are equally important as they are opinion builders and shapers who have a major role to play as functionaries in the local

area. Some of the important functionaries are doctors, nurses, school and college teachers and other service providers. Awareness has been built amongst these groups through their study visits, resource lectures and short training programmes designed for each group.

It is a great accomplishment of the Institute that today even the National Academy of Police, has included Thakur Hari Prasad Institute in their recent field visits for police constables and other higher officials.

In addition, students of the following categories are also contributing towards research:

- Post-Graduates in Social Sciences like Home Science, Psychology, Sociology, Dip. in Early Childhood Education
- Graduates and Post-Graduates of Teacher's Training Programme (Bachelor of Education and Master of Education)
- Pre-School Trainees.
- Nursing students from various institutions
- Medical students from various branches
- Social Work students and so on.

REFERRAL SERVICES have also had its impact on other professionals in the community. In this way, some of the leading hospitals in the city have come forward to extend their support to rehabilitation programmes. The result is a series of camps organized for the benefit of people with mental handicap viz. eye camp, E.N.T. camp, dental camp and so on. Inviting them for seminars, resource lectures have been other means of sensitizing them.

## **9. Information at Policy making level :**

It is a fact that no programmes however good and scientific can have a massive effect, or national impact unless the policy makers and politicians who plan, rule and shape the national development programmes are convinced, motivated and committed to it. Being aware of this, THPI has not over looked their role in its programmes and the role played at the national level.

It is a global credit to THPI that two historical seminars on Indian soil viz. "All India Seminar to Frame a National Policy for the Mentally Retarded in 1987" and "XI World Congress of ILSMH" in 1994 have been organised by THPI.

The first seminar which was attended by parents of mentally handicapped, professionals, policy makers and people from all other areas, resulted in a Policy Document which was presented to the then Prime Minister Sri Rajiv Gandhi. This resulted in the constitution of an inter-ministerial

committee to look into it. This policy document resulted in a Bill for the disabled awaiting its enactment, and many other significant developments such as the formation of 'National Forum for Welfare of the Mentally Handicapped', National Trust, Rehabilitation Council towards the standardisation of curriculum in the field of rehabilitation and so on. It may also be noted that all things are not as rosy as they look.

Sometimes there is opposition by vested interests, to immunize the politicians and policy makers who are being exposed to an awareness building process. It did happen to us on various occasions. The message therefore is that there should be strong media support to overcome such pressures and to come out of them successfully.

The XI World Congress of ILSMH apart from bringing rehabilitation professionals from 102 countries, and promoting sharing and exchanging of information, knowledge and skills, also created an awareness wave all over the country. Media print, electronic and air gave a wide coverage of the programmes resulting in a wide publicity of the issue of Mental Handicap. The Ministry of Welfare was deeply sensitized. It resulted in hundreds of letters pouring into Thakur Hari Prasad Institute from politicians, professionals, media persons and parents seeking information.

The THPI very often invites a political leader along with a professional to inaugurate important programmes. THPI also makes it a point to give a brief glimpse of the institute and of the mentally retarded people at work, at training and so on, because most of the time the visitor is exposed to the world of rehabilitation of people with Mental Handicap for the first time. Subsequently they were willing to listen to issues that were related to these people. This resulted in long-term support extended by a few and sensitization of many others. To say the least, we made them aware of the existence of people with mental handicap.

A forum of Members of Parliament has been created and around fifty MPs have promised to support the cause, which itself can be a great source of strength.

## **10. Concluding Remarks :**

An important information system is vital for the rehabilitation of people with disabilities, more so for people with a mental handicap. Information is indispensable to sensitize people at all levels about rehabilitation needs, to build-up awareness, to empower people with skills and motivate them into action. The target group therefore does not confine to disabled persons alone, but includes a wide spectrum of all right from the top policy makers to the down trodden people in rural and urban areas. All of them have some function or other to carry out. These groups need to be enlightened and empowered.

Quite a lot of indigenous information materials rest with the families and community members eg., the family that develops its own auditory stimulation for deaf children through

chanting of verses, singing songs and so on, the local welder or carpenter who creates exercise apparatus for spastic children and for other motor handicaps, the sibling who reads the newspaper to his/her visually handicapped sister or brother, the grandmother who stimulates the speech of an infant through story-telling, the age-old massages given to the infant and many other things. These generation old techniques can be utilised and implemented to achieve the desired results and used for a wider sharing through documentation.

The needs of the target groups vary viz. the mother who was just been told about the handicap of her new born child, a parent who is desperately in need of a vocational training centre that would train his/her adult son with a severe mental handicap, a general practitioner looking for literature to guide parents, a school teacher wanting to know how to assist a child with poor academic performance, a professional trying to know how to support and guide a family with an adult female who is totally dependent on her family for her daily skills and so on. These various needs can be fully met by the optimum utilisation of the media. There is no limit to the utilisation of media to meet any challenging need and demand. Therefore, in the present context in developing countries where there is a little prospect of current methods of generating sufficient skills and resources to provide special training and rehabilitation services for more than a fraction of those needing them, INFORMATION BASED REHABILITATION offers a low-cost strategy to benefit the largest number. Dissemination or mass transfer of knowledge, monitoring and evaluation of appropriate information leading to self-generating information systems is an approach which is accessible to developing countries and should be considered as a realistic alternative available for EMPOWERING disabled persons, their families and community. Therefore rehabilitation needs to be redefined as information based. This information-based rehabilitation can be replicated to reach millions of disabled persons with knowledge and skills.

# 'Bureaucratic Procrastination' & 'Burgeoning Population' are twin dangers

The socio-economic situation in many of the developing countries, particularly those of Asia, is accompanied by common symptoms of backwardness - high birth and death rates, low rates of literacy and life expectancy, poor health and housing conditions, low levels and poor quality of nutrition and lack of education. Unfortunately, in most of these countries, the above have been seen only as economic problems. Accordingly, many economic measures have been tried out to solve these problems which also include meeting the social needs-at some stage. But economic development of the required level never took place in many countries. In countries and regions where this miracle did occur, it was not accompanied by social development, as expected. Even where there was a remarkable increase in national income in terms of gross national product, social conditions either remained the same or actually deteriorated. In India it has been accepted all along that economic development should not be considered an end in itself. It should be only a means to attain social development, defined as economic development with social and distributive justice. The benefits of development are to be distributed among all, and not to be confined to small groups at the top. The experience in India has been that economic growth did not often reduce disparities in income or concentration of wealth. Even where successive five year plans tried to bring the economically and socially disadvantaged groups into the mainstream of development, favourable impact has been limited. Hence, planning for social development must go far beyond the mere provision of social services or securing of economic growth. It should concentrate on improving the quality of life through judicious use of all resources, particularly human resources in a judicious and balanced manner.

The direction of social development in India has been clear, though the movement towards the social development objective has been rather slow. The main objective of raising the standard of life of the people, nearly 40 per cent of whom are living below the poverty line, has been a far cry; something easier stated than achieved. Among the developing countries, India has been considered a soft country, where even the hard decisions on implementing land reforms, checking corruption and preventing tax evasion have been diluted and watered down to such an extent, that the laudable objectives originally put before the country have often been frustrated by poor and half-hearted implementation.

As in many developing countries, faced with the problem of population explosion, coupled with very low standards of living, in India also there has been a feeling that whatever progress has been achieved in the economic field is being totally wiped out by the population growth. In other words, increasing population has been seen as a drain on the meager resources of the country and a dead weight preventing the progress of the nation. But the most surprising thing is that by a change of outlook and perspective, the same human factor which seems to be eating into the resources of the country, can be converted into the most powerful and potent factor of production. The basic consideration in any process of production is that it be locally available and abundant, and therefore the factor of production is made greater use of. That is why in India we are faced with a fact, stranger than fiction, that all the other factors being limited, the only factor, the liberal and judicious use of which can boost-up production in all fields and ensure progress, is **manpower**. That is why human resources development becomes the most important task as the maximum use of manpower becomes crucial for the success of all social development projects.

What is most significant in any social development effort is the involvement and direct participation of the people through the projects taken on hand. If we take the example of the marginal farmers, backward or neglected groups in rural or urban areas, perhaps the greatest hindrance to their progress is the attitude of the people themselves, due to their passive, pessimistic and individualistic approach. Human resource development must bring about a change in the hearts and minds of these people, after which they should be active, optimistic and socially committed people. After instilling confidence in them and in their own capacity, they should be trained to develop the necessary skills and update their approach. Appropriate orientation and training, may be in agricultural methods, subsidiary occupations or cottage industries, they can be fully involved in income generating projects. Women's organisations and youth clubs in different parts of the country have a significant role to effect social development through people's organisations.

Very few people now a days subscribe to the traditional economic interpretation that once the economic conditions improve, the social conditions would automatically advance. Actually the experience in different parts of India is that following the green or white revolutions or success in other income generating projects, there has been affluence among certain sections of the population. But what happened in many instances has actually been a deterioration in the quality of life. One would have expected that following improvement in economic conditions, there would have been enhancement in social conditions leading to better health, enrichment of family life, spread of education. Instead, the extra income has been found to be spent on activities such as drinking and gambling which are socially harmful.

Social developmental thrust has also been adversely affected by the poor quality of services in the areas of health, education and housing, which can be termed as items of investment

in human beings. These help develop the human resources to an extent where they become both the means and ends of, social development. There are also regional imbalances in governmental and voluntary sectors' programmes. For example, if we go by the expenditure on health and education, it is seen that the bulk of the programmes benefit mostly the small percentage of people in the urban areas.

There is a neglect of rural areas and particularly the far flung areas where the tribal people live isolated and cut off from the other people both geographically and culturally. All programmes in the governmental and voluntary sector in the field of social services and welfare facilities will have to be so distributed that they particularly serve the people in the backward areas. In this way they are helped to come into the mainstream of the society along with the other advanced groups. India is one country where constitutional provisions have been made to protect the interests of the weaker sections. This is to allow them to have their legitimate rights in their struggle to catch up with the rest of the society over a given period of time.

There was a time when professional social workers in many countries, including India, used to take only a very limited view of their technical functions. The background of mass poverty, and other problems of deprivations and backwardness, in India and other developing countries has rendered the task of social development more challenging. Social workers have to shed their narrow and limited approach and accept responsibility for wider and fuller involvement in social development.

In the light of this situation, even the goals of social work have to be seen not only as they exist today, but as they need to be developed in order to meet the emerging needs and challenges. The general goal of social work of helping individuals, groups and communities to lead personally satisfying and socially useful lives is accepted universally, but its relevance in different conditions can vary very much. Here in India, working for, and with few individuals or groups alone will not help deal with the massive problems that are faced by the nation. Hence, in Indian conditions, the role of motivating individuals and groups to adjust to their needs or to react adequately to given situations is useful, but only upto a point. The more fundamental work in India and other developing countries is to bring about radical changes in the social and economic systems to correct the existing injustices and imbalances. Hence the social workers' role as a change agent is to be less with individuals and more with total social and economic groups in the country. This will be possible through positive, purposeful and even aggressive participation in social development to change the economic and social contours of the country. In this task, skills in social planning, social policy analysis and formulation become very important.

Social developmental issues are specially important in developing countries such as India. The schools of social work in Asian countries, in addition to their existing graduate and postgraduate programmes, will have to provide training and orientation at the level of

the community, for para-professional personnel. The need in the field of social development, particularly for direct service functions in the backward areas, and with economically and socially disadvantaged groups, will be more for grass-root or intermediary level workers. Hence, in addition to post-graduate training of personnel for higher levels of supervisory and management positions, schools of social work wanting to be involved in social development, must equip community workers with necessary knowledge, aptitude and skills needed for social developmental functions.

The developmental thrust has been successfully reflected in India in a very special way because of the large number of social developmental projects started in many fields. Since well-trained, properly equipped and motivated workers are the ones who can successfully handle these responsibilities, special short-term training programmes, or integrated courses at undergraduate levels will have to be evolved, to meet the needs for personnel for social development. Such special training programmes must be devised keeping their objectives, content, and duration in line with the functions and special needs in the field of social development.

Social Workers will not be able to discharge their responsibilities in social development unless they are able to forge a 'united front' with several other individuals and health groups particularly in helping the connected professions. Social workers will have to effectively play the role of a team member, some times leading, and some times following those in a group. In the field of social development, which is by and large, a rather unchartered one, this kind of collective responsibility will have to be exercised. This collaboration with other professionals and partners will greatly help in economic and social planning, in medical and social services, in town planning and urban improvement. This approach is necessary in order to work out an integrated action plan to eradicate major problems such as ill health, illiteracy or other deprivations. In such an integrated group effort, what is significant is the total contribution of the whole group.

Another aspect of Social Work in the development context, particularly in countries like India, is the need for wide range of preventive and promotive programmes in all fields in which social workers are currently operating. But this does not mean that the very useful services in the fields of remedial, residual and corrective action, where our skills and expertise are well recognised, are to be neglected. The best course before social workers would be to strengthen all the areas of current operation, dove-tailing them into the developmental tasks, which are now becoming more and more significant in the context of the country's over all development.

If social workers are to play an effective role in social development, their training will have to be geared to not only the present day needs but to the needs that are likely to emerge by the year 2000 and beyond. This will have to be done according to the national and regional conditions. Keeping the general background of developing countries, it can be said that while

Social Work curriculum should undergo changes, it should remain broad based and flexible enough so as to add social developmental dimensions as they are today, and even as they develop further. Every time when curriculum changes are attempted, the overall professional and social objectives are all to be kept in mind. The full implications of the widely prevailing problems of poverty and other economic and social evils must be closely studied, and the knowledge and practice must be based on the historical, cultural, social and anthropological background of the country against which these problems are to be remedied. Students will have to be increasingly sensitized to these problems by new developmental programmes, that basically build the inner confidence of the people, and help them to realise the full potential of the manpower resources they represent.

What is needed urgently is that the skills of working with individuals and groups are integrated with the needs and problems of the community so that Social Work methods are used in an integrated way.

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# Developing Linkages between Rehabilitation Council of India and the International Organisations to Workout Strategies for Meeting the Challenges in Rehabilitation of Disabled Persons

Rehabilitation International was founded in 1922 in USA as the first international effort to stimulate services for crippled children. RI has grown into a world wide organisation influencing policies and providing services for disabled children and adults in more than 120 countries. Rehabilitation International enjoys Chief Consultative Status with all UN agencies viz., UNDP, ILO, WHO, UNICEF, UNESCO etc. This is the year of 75th Anniversary of the Rehabilitation International.

From the beginning leadership of RI focussed on international **policy** campaigns that could be implemented at the national level. One of its first achievements was the presentation of a ten point Bill of **Rights** for crippled children to the League of Nations. In 1929 in Geneva, the organisation launched its series of World Congresses, held every four years to stimulate and review progress on an multidisciplinary level. Its headquarters are in New York and works in close proximity to the UN Family of Agencies and by the early 50s had established official linkages, to ensure that the UN included disabled people in its developmental plans, the **UNICEF** extended its services to disabled children, the **ILO** supported labour initiatives for disabled people, the **UNESCO** added special education to its mandate and **WHO** focussed on disability and rehabilitation, not just diseases.

Rehabilitation International works on international human and civil rights movements. The RI was the first to demand the end of segregation of any group on any basis and also calls for the end of **institutionalisation**, the beginning of **normalisation** and **integration**.

Rehabilitation International was the first international organisation to hold World Conferences advocating comprehensive disability legislation and it was the first in the world

to bring international awareness of architectural and environmental **accessibility**, leading to the adoption in 1969 of the **International Symbol of Access**. In retrospect, the symbol was a graphic indication of a turning point in the disability/rehabilitation movement - the beginning of the adaptation of the physical environment to the needs of people with disabilities - in essence, a revolt against the previous concentration on teaching and counselling the disabled persons on how to adapt to society.

In 1969 RI authored a report on the needs of developing countries, the first outline of what became known as **Community Participative Rehabilitation**, an acknowledgment that the approach of the industrialized countries was not applicable to the Third World.

### **The Contemporary Era:**

On the international scene, most rehabilitation specialists agree that the contemporary era was launched by the **United Nations** when it proclaimed 1981 as the International Year of Disabled Persons, which "credentialed" this population as a recognised minority group in relation to developmental assistance and international aid.

RI's **Chapter for the 80s** comprising of four main aims are still relevant today: disability prevention, provision of rehabilitation services, equal participation and increasing public awareness. It contributed substantially to the many United Nations initiatives, the **Decade of Disabled Persons** and the **Standard Rules** for Equalisation of Opportunities for Persons with Disabilities:

Global statistics on the incidence and prevalence of disability were developed by RI, which resulted in the widely known estimates that one in ten persons is born with or acquires a disability; and that there are more than 500,000,000 disabled children, men and women around the world. Two-thirds of these persons with disabilities live in developing countries;

Collaboration with UNICEF for 15 years in the era of **childhood disability** has resulted in seminal field studies on the lack of rehabilitation services for children and women in war-torn areas, as well as for the need of international action against **landmines** and **organised violence** which cause intolerable levels of disability and trauma;

Considering the growing trend of self-representation among groups which experience discrimination and disadvantage, RI has in the modern era become more **inclusive** of disabled people within its leadership, member organisations and network, as well as increasingly **collaborative** with international organisations with similar goals in the disability field; and

As the 20th Century concludes RI has rededicated itself to concentrate on the **global policy of networking, leadership in rehabilitation, equalisation of opportunities and disability prevention**.

The United Nations Statistical Division at its New York Headquarters has revealed that a world average of one in six persons is an individual with disabilities. 30 years ago, the Rehabilitation International (RI) and the World Health Organisation (WHO) made news by saying that, based on a global survey, one in 10 individuals had a disability. Reflecting on developments globally, RI has become increasingly regionalised with regional offices, conferences, organisations and publications, based on recent studies, census-taking projects and deliberations. The United Nations Statistical Division has compiled the data.

What has not changed during the last 25 years is that the prevalence rate of people with disabilities in developing countries has remained greater than that in developed countries. Children with mild, moderate or severe disabilities numbered around 150 million in 1990. The United Nations Development Programme (UNDP) 1993 states that 2300 additional children are added to these numbers every day through trauma and injuries. Therefore, the number of people in the world with disabilities by the year 2025 will double. However, the disparity between the developed and developing countries will widen, the developed countries will show a decrease of 14% between 1992 and 2025, while the developing countries will show an increase of 47% in the span of 35 years. The world's children (0-18 years) number over 2 billion. Nearly 9 out of 10 of them (87%) live in developing countries. (UN Population Division, World Population in 1994 Revision, United Nations, New York, 1995 in the State of the World's Children 1997). The global demand for rehabilitation is and will continue to respond to changing conditions in the populations. While society may possess the technology to deliver the service or build the equipment, the availability of the rehabilitation technology is often not located in the same geographical place where the demand is the strongest. Worsening conditions among populations in diverse parts of the world will stimulate individual demands for rehabilitation supply as never before.

### **Functions under siege:**

Basic societal functions are under siege; covering food production, shelter, clothing, clean water supply, education, establishment and preservation of family structures and income generation. Erosion of ability to carry out several functions will create risk factors, increasing the likelihood that rehabilitation will become necessary. **The definition of Rehabilitation uses a broad based application here “an intervention used in situations when there is a need for persons to relearn functions because an impairment has affected”.**

In order to comprehend the intricate magnitude of the problems now leading to increased demand for rehabilitation, interested people should consider new information sources – information not likely to appear in the formal medical journals as helpful tools describing diverse country conditions now leading to increased demand for rehabilitation of the physical, mental and if need be spiritual status. We have to popularise the publications as Thakur Hari Prasad

Institute's Sankalp, International Rehabilitation Review etc., which regularly publishes articles that highlight innovative programmes.

Currently, there are numerous examples of applied rehabilitation practice models which have been built on successful Medical, Clinical and Psychological implications. The question to be asked is why have not such models found their way into the mainstream of development now undertaken by such bodies as World Bank, Regional Development Banks, UNDP, ILO, WHO, UNICEF, UNESCO and within our respective countries aided programmes? Why Community Participative Rehabilitation, by way of providing concrete outcomes, despite its attention within the literature, as a conference topic and as a focus of highly publicised projects by highly visible organisations have not yet achieved the status of generally accepted national policy?

Till recently, the question has largely been a rhetorical one. The question now merits significant and practical attention by those who know how to bridge policy and programme implementation with effective tools. The time is right. World Development Organisations have officially acknowledged through United Nations Conventions and Policies, that economic and social development strategies have not worked as well, as had been hoped for.

Development Organisations are retooling their strategies. UN Documents have emerged at the Convention on Elimination of all forms of Discrimination Against Women (CEDAW), Convention on the Rights of the Child (CRC), the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and Declaration and Platforms for action produced and ratified by UN Summit delegates attending 1995's World Summit for Social Development in Denmark and the Beijing World Conference on Women; these provide substantial documentation about the un-met needs of the vulnerable populations including people with disabilities. Sufficient policy exists to launch developmental efforts including the rehabilitation, as a central implementation strategy.

The Delhi Declaration of XI World Congress on Mental Retardation organised by National Forum for Welfare of the Mentally Handicapped and Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped held in Delhi, in 1994 was a significant step in the right direction in fulfilling the above strategies.

### **Building up Human Capacity:**

One of the occupational hazards in today's work environment is that we are so caught up with doing, that we do not stop to reflect and document the effectiveness of past and present practices. Worse than that we do not systematically disseminate the knowledge about the effectiveness of models of practice. If we do disseminate all too often, we are now speaking to other members of the choir, the reason being the existing communication patterns established themselves due to existing relationships formed among kindred spirits – professionals of one type form their organisations and international bodies and talk to each other. Our behaviour

If rehabilitation models are offered to be adopted as good investment strategies in the 21st century, then they will have to prove their worth through cost-benefit tests or other tests. While case studies can be used to teach the effective programme and policy models, there is a real need for valid reliable data to provide a solid rationale for the use of a rehabilitation model in development.

The United Nations now houses a useful disability data-base named the UN Disabilities Statistics Data Base (DISTAT) composed of valid and reliable descriptive information collected from about 120 countries. The objective guiding DISTAT's data collection design centres is the potential usefulness of the data's application to policy and programme development. The data describes broad categories of persons with disabilities' functional limitations. This approach augments the earlier approach relying on "head count".

### **Recommendations:**

*In conclusion, the following immediate Needs on Disability in the Developing Countries demand attention:*

#### **1. Training of the Trainers:**

Training packages need to be developed for training the trainers at different levels i.e.,

- 1) for professionals working with disabled;
- 2) professionals not connected with the rehabilitation process, so that, disabilities can be detected at an earlier stage;
- 3) training of para-professionals and community health guides;
- 4) people who come across the target population, like teachers from normal schools;
- 5) village leaders.

The training programmes need to be of different duration i.e., long term, short term etc. There should be exchange of experiences between institutions in developed countries and developing countries, and collaboration between individual countries and among ministries involved in work with disabled.

#### **2. Adaptation and Translation of Techniques and Technologies to Local Conditions for the benefit of Disabled:**

Development of science and technology in our country for the disabled is in its infancy. There is need for innovative and creative thinking for development of methodology and its application in this area. Facilities should be developed for assessing the residual ability of persons with disabilities, so that these skills can be best utilised. Adaptations in machines

- f. Monitored and sustained follow-up. Sustainability is most crucial even after initial support is withdrawn. "Anveshana Project" on prevention, early identification and intervention for persons with disability launched by Thakur Hari Prasad Institute, Hyderabad, India is a successful model which is still in operation.

## **6. Strengthening Families:**

In most developing countries, the burden of caring and training children with disability particularly persons with Mental Retardation, primarily falls on the family. We therefore have to promote family-oriented services, through centre-based individuals model, centre based group activities like parent-professional meetings, family cottages, parent to parent support, group parent training programmes, sibling groups, parent self-help groups, promoting cooperation among parent organisations.

## **7. Role of Media in creating Awareness:**

Media plays an important role in society today. Awareness about disabilities and the potential of persons with disabilities needs to be created among families of disabled persons, community planners, decision makers, employers, academicians etc. Print media along with electronic media i.e., Radio and T.V. will have to play a very important role. Media can play a useful role in disseminating information about disability to the general public, remove myths from the minds of the people regarding disability and educate them about the abilities of the disabled.

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## Profile of Thakur Hari Prasad Institute

The Thakur Hari Prasad Institute (THPI) a voluntary organisation with three decades of field-based experience in Mental Retardation, is an organisation that aspires perpetually for excellence in services to promote the quality of life of persons with Mental Handicap. It was established in the year 1968 by a parent Dr. Thakur V. Hari Prasad. It is the culmination of the manifestation of his humanitarian concerns and scientific temper. Staffed by qualified faculty in Neuro-paediatrics, Psychiatry, Clinical Psychology, Special Education, Speech Pathology and Audiology, Physio Therapy and Occupational Therapy, the institute also offers augmentative interventions to supplement clinical therapies through Dance Therapy, Music Therapy, Yoga, Hydro Therapy, Art Therapy, Horticulture Therapy etc. The Institute has great concern for environmental hygiene and maintains a picturesque landscape at its campus, both at Hyderabad and its Rural Project, at Lalacheruvu, near Rajahmundry.

The service-users of THPI belong to all strata of society both urban and rural. The organisation is very secular bringing into its fold beneficiaries and team members hailing from different parts of the country, following different faiths. Thakur Hari Prasad Institute has been a trend-setter in many ways which brought about many unprecedented outcomes for the benefit of people with disability, nationally and internationally.

The progress in the field of Rehabilitation in the past two decades in India owes not a little to the perseverance of THPI to improve, update and promote quality of services for persons with disabilities in the process national and international acclaim. THPI's concern for persons with disabilities, especially those with Mental handicap transcends the Indian boundaries, to provide a better quality of life for persons with disabilities globally. It has made several strides in National Level initiatives for promoting quality of life of persons with disabilities, and has created history as an NGO by initiating a National Policy on Mental Handicap, a State Policy for all disabilities and bringing about legislations in the field of disability. The THPI hosted the World congress on Mental Retardation, organised an International Integrated Children's Summer Village Camp and many such initiatives which stand as striking illustrations of the borderless world of THPI while addressing issues related to the problems of disabilities and rehabilitation. Among the services offered are prevention, diagnostic assessment, early detection, early intervention, integrated early education, integration, special education, foster-care-home services, vocational training, career guidance, employment, post-employment monitoring, sex and marriage counselling, therapeutic interventions through traditional arts - performing arts and visual arts, hydrotherapy, Yoga, etc. In all its services, the emphasis

is on a comprehensive multi-disciplinary approach by involving team members at apex, mid-level and grass-root level who interact in interdisciplinary and multi-disciplinary forum. Emphasis is also laid on empowering family members with skill, knowledge and attitudes to support persons with Mental Handicap as co-therapists. Direct services are extended to over 11,000 beneficiaries with Mental Handicap annually at the Hyderabad centre and 5000 beneficiaries at its Rural Project at Rajahmundry. Many innovative programmes with viability for replication at National and International level have been initiated by the organisation. The quality of services with very systematic documentation have enabled THPI to assume the role of a resource centre for many field-based researchers.

THPI has been represented internationally at various conferences, congresses, seminars and workshops by its President Dr. Thakur V. Hari Prasad. Many culturally relevant models of service-delivery, scientifically field-tested experiences and explorations of THPI have been shared in such forums.

THPI has also invited many internationally renowned professionals as resource persons for workshops and seminars at Hyderabad which were attended by delegates from all over the country.

The urge to cater to rural people's rehabilitation needs resulted in designing a **Rural Camp Approach** to detection, intervention and follow-up of services for persons with Mental Handicap. To date the THPI, Hyderabad and Rajahmundry have conducted innumerable rural camps. Individuals with other disabilities are also supported and referred for appropriate services. **The philosophy behind the camp approach is the convergence of existing services and also community participation.**

THPI is involved in Human Resource Development at all levels. Apart from pre-service training programmes, in service training, refresher programmes and crash training courses for different target groups are offered. The human development approach is applied to internal professionals who are always encouraged to improve levels of competencies and also the development of personal efficacy.

'Integration' means much more than 'desegregation' to THPI. It implies 'inclusion' in as many opportunities in the mainstream as possible to as far as can be achieved with no compromise on efforts to meet the special needs and challenges caused by disabilities. The lessons of integrating children in pre-schools and primary schools and adults in supported open employment in the community both in the urban and the rural centres of the Institute, led to the cost-effective mode of value-addition to the quality of life of persons with Mental Handicap.

- \* Rehabilitation of children and young persons with Mental Handicap under **judicial custody**. Since 1985 THPI team conducts annual screening of children at the Govt. Juvenile Home for boys. Those identified as Mentally Retarded are brought to THPI campus daily along with an escort provided by the Government after clearance of necessary permissions. All individualised interventions are offered to them apart from systematically planned educational / training programmes. It is another first time effort in the country. It indicates the pro-active nature of the organisation to search and provide rehabilitation for persons with Mental Retardation.
- \* **Foster-care-homes** - A service model that is unique in India, is the residential setting of THPI called Foster-care-homes. Under the guidance of a trained Foster-care-mother 4 children live in individual cottages, learning and participating in activities of daily living in a very homely environment.
- \* **Graduation** of persons with Mental Handicap is another first time initiative of THPI. As a believer in equal opportunities and equalisation of services, the founder Dr. Thakur V. Hari Prasad, supports and encourages efforts to promote the gradual developmental accomplishments of persons with Mental Handicap with a formal graduation ceremony. This received wide appreciation in the field of Rehabilitation.
- \* The field of Mental Retardation and other disabilities are relatively unexplored areas as far as research is concerned in our country. As an NGO with a commitment to qualitative service delivery and innovative, cost-effective models, strategies and approaches, THPI has to its credit many field based action researches which have resulted in evolving of large scale programmes and development of existing programmes. The institute places a high priority on research and documentation that hold national or international relevance. Apart from regular ongoing research programmes of the faculty, research projects undertaken by Post graduate and research students of different universities are conducted and supervised by THPI. In order to promote research in the field of Mental Retardation, the institute has announced a **research fellowship** for university researchers pursuing doctoral research in Mental Retardation. THPI has to its credit many publications based on its own research programmes.

The Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped has been described by many a visitor from different countries as an oasis in the field of Rehabilitation. Its concern for people in need of qualitative services transcends mere statistical numbers and encompasses the individuals and their families as integral members of the society. Its three decades of continuous growth has added to its capacity in enhancing the quality of life of several thousands of individuals with disabilities and also their families.