

HRD in disability rehabilitation – Role of Csos with Ethics

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ABSTRACT

Disability is the barrier for development which works as cause and consequence of each other that further deepens the poverty. The disability population is quite high and alarming the stakeholders for developing effective strategies and interventions for identification, rehabilitation including prevention. This further marginalizes them with isolation and invisibility. At this stage the concerns of Persons with Disability (PWDs), and their parents that ‘nothing about us without us?’ and ‘what will happen to the child after us?’ respectively needs better solution with ethics and values. CSOs are the key players in coordinating the Government, PWDs, Parents, Siblings and other departments for reaching the groups both quantitatively and qualitatively with effective service delivery systems. The study made with CSOs, Parents, Siblings, & PWDs each 15 samples with developed questionnaires has clearly reflected that they are very much committed for the cause of disability rehabilitation including prevention. The study has opened scope for detailed research and to address the issues of disability with innovative and creative problem solving solutions with better sustainability and quality.

Statement of the Problem

Poor availability of Human Resources in Special Education affected Disability Rehabilitation including its prevention and thus the dynamics of Disability Sector are alarming with increased invisibility and isolation of the Persons with Disability at all levels.

Introduction

Disability is the real barrier and affects the development at all levels which further

deepens the poverty as ‘*Poverty, Disability and Development*’ are the cause and consequences of each other. The causes for disability are many and certainly poverty and health care gains priority in general and additionally consanguineous marriages do contribute significantly for the cause of mental retardation and other associated disabilities which are broadly grouped into ‘Intellectual and Developmental Disabilities (IDDs)’. Then the question arises ‘what to do?’ with the

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‘Persons with Disability (PWDs)’ in general and particularly ‘Persons with Intellectual and Developmental Disabilities (PWIDDs)’ who need supports on ‘Life Cycle Approaches (LCA)’. Then the question of ‘who will do?’ follows. It is the team of professionals with special education, physiotherapy, speech & language, disability administration, orthotics & prosthetics, and other allied areas. All these professionals need suitable platform to work for the rehabilitation of the PWDs as well as to prevent the disabilities to the maximum extent possible with multidisciplinary approaches. ‘Government (GO)’ both State and Central govts. are doing their best in this regard and are constrained by several limitations as majority of their strategies/interventions are mostly based on the ‘Top Down Approach (TDA)’ with limited connectivity with the PWDs and other stakeholders at the grassroots level. The Persons with Disability Act (1995) and its amended form, Rights of the Persons with Disabilities (RPWD 2011) along with the United Nation’s Convention on Rights

of the Persons with Disabilities (UNCRPD 2006) provide provisions for the rights with protection, participation and inclusion. Based on the Census (2011), the disability population is around 3% (expected to be much more than this) which is alarming. In addition, the concerns of PWDs that “nothing about us without us” and that of parents “what will happen to the child after us” still waits for better platform with matching solutions. At present the reach of such provisions to the PWDs are mismatching both quantitatively and qualitatively. Understanding such limitations and gaps, ‘Civil Society Organizations (CSOs)’ came into existence to support the Government for effective implementation with ‘bottom up approach (BUA)’ which majorly concentrates on the skills, needs and vulnerabilities of PWDs along with their parents, community.

Among the gaps indicated as above, the serious one is non availability of the professionals with special education. Under the guidance of Ministry of Social Justice & Empowerment (MSJ&E), New Delhi, Rehabilitation Council of India (1992) develops courses from Certificate to Masters and approves the Institutes, Universities and Organizations (CSOs) to run such courses both on Regular or Distance mode or both. As per the status furnished by RCI, registered professionals are 67,738 (till November 2011) against the requirement of 7,24,000 (based on 10th Plan of GOI). This indicates wide gap to address the needs of the Disability Sector as well as to move towards the creation of ‘disability free Nation (DFN)’.

At this stage, CSOs do play significant role to develop the human resources in special



education with ethics and quality so that PWDs can be reached early with effective and transparent strategies & interventions with the combination of TDA and BUA. The proposed study mainly concentrates on this to develop ethics and quality based special education with emphasis on '*distance mode*' both at development and implementation stage. These comprehensive approaches of CSOs along with GO are expected to minimize the impact of disability on development and '*quality of life (QOL)*'.

As indicated in Fig.1, Disability Rehabilitation is the State subject but works with the support and coordination of the Central Government having Ministry of Social Justice & Empowerment (MSJ & E), National Trust (NT), Rehabilitation Council of India (RCI), National Institutes (NIs) under its umbrella in association with the Universities and Civil Society Organizations (CSOs). With the approval of RCI, several Institutes / Universities / CSOs conduct courses in special education either on conventional mode or distance mode or both. CSOs work with the PWDs, and their parents & siblings along with Professionals and other service providers. This integrated approach leads for availability, accessibility and affordability of services / supports which further leads for: better Reach, Connectivity, Participative, Social Audit, Transparent, Ethics and Quality within the inclusive community. This finally leads for the empowerment of the targeted groups for leading improved quality of life (QOL) with sustainability. This also works effectively for the prevention of disabilities leading for disability free Society (DFS) which

finally minimizes the impact of disability on poverty and development as they works as cause and consequence of each other.

Objectives

The study concentrates with specific objectives in improving the ethics and quality professionals in special education which include:

- To understand needs, concern and vulnerabilities of the disability population,
- To understand the advantages and limitations of service delivery channels,
- To explore alternatives of HRD in special education,
- To make SWOT of GO & CSO, and
- To suggest ways for improving the ethics and quality.

Literature Review

The literature review has been carried with reference to the special education through distance mode by the CSOs and found limited studies. The researcher himself has done some work and its salient features are furnished below as:

Lakshmi Narayana N (2012): In the paper published in Annual Hand Book of Human Resources Initiatives, Initiatives and Interventions, New Delhi, author specifies the role of RCI, IGNOU and NGOs (CSOs) for developing the Human Resources in the Disability Sector which includes:

Role of RCI:

- Framing of the Course, Syllabus (more practical with placement) and other required guidelines.
- Framing of recruitment rules (RR) & regulations for employment.
- Creation of suitable posts in all the departments.
- Review and monitoring process for time to time evaluation & amendment if necessary.

Role of IGNOU:

- Enhancing its present networking to cover the major part of India.
- Networking with Government, RCI, National Trust, Universities and other concerned departments for enhancing resources & capacities.
- The Regional Centres to be strengthened with the Universities and other service providers situated in the capital itself.
- Allotment of Study Centres to the service providers like: NGOs, DPOs, CBOs, PAs Opportunity to be given for the small service providers to collaborate with other institutions / organizations for running such study Centres.
- Strict review and monitoring process for better implementation.

Role of NGOs:

- Ready to accept for running the study centres for the courses concerning with Disabilities in which it has got capacities.
- Enhance its professional skills to run the educational courses.

- Networking with Universities, National Institutes and other allied departments for getting faculty and referral services.
- Sensitize and motivate the needy to join in the stream of professionals for the most needy disability sector.

These studies with SWOT Analysis of contributions made by the Government and CSOs reflect the fact that attempts have been made to strengthen special education through distance mode with specific role by RCI, IGNOU, & NGOs. In spite of best efforts in this direction, it is the reality that required human resources matching to the needs of disability sector could not be achieved. There is a need of strengthening educational systems in India with more emphasis on distance mode of special education with greater role of CSOs for working as a Study Centre (SCs) with efficiency to effectively reach targeted HRD both quantitatively and qualitatively in general and particularly in the rural areas where around 70% of disability population is expected to live.

Hypothesis

Availability of professionals in special education helps to reach the targeted groups with effective role of CSOs for identification, rehabilitation and prevention.

Methodology

The methodology adopted includes the search of websites, observation, interactions, trainings, workshops, seminars and data collection from 60 samples covering parts of Andhra Pradesh (united) by way of developed questionnaires with simple stratified random sampling technique covering CSOs (15 no), Parents (15 no), Siblings (15 no) and PWDs (15

no) with 15 no of questions to each group i.e., 225 responses for each group and thus totaling of 1,000 responses.

Data Collection, Presentation and Discussion of Results

Initially the figures have been collected with the help of websites of the Government Departments, National Institutes, CSOs and other forums of disability sector. The data has been collected from the targeted groups at special schools, consultations, meetings, trainings, workshops, seminars, home, and communities. The collected data has been formulated and presented in the form of diagrams (pie) and were presented below along with the reflections and results.

As indicated in the introduction, the search of the websites of the concerned disability departments reflects the actual status that the disability population is not mapped accurately and expected some deviations; grant support by way of schemes and benefits both directly or through the CSOs is not matching; human resources in special education are not matching to the requirement; ineffective service delivery systems limits the reach to the groups both quantitatively and qualitatively; measures are not effective in preventing the disabilities; and insists for strengthening the CSOs at community level.

CSOs: This group reflects (Fig.2) that they are committed for the cause of disability rehabilitation (6 with 40%); do not feel much difference (6 with 40%) with the professionals done the courses in special education either on conventional or distance mode; and partly (3 with 20%) feel the shortage & non availability of professionals in catering the needs of PWDs

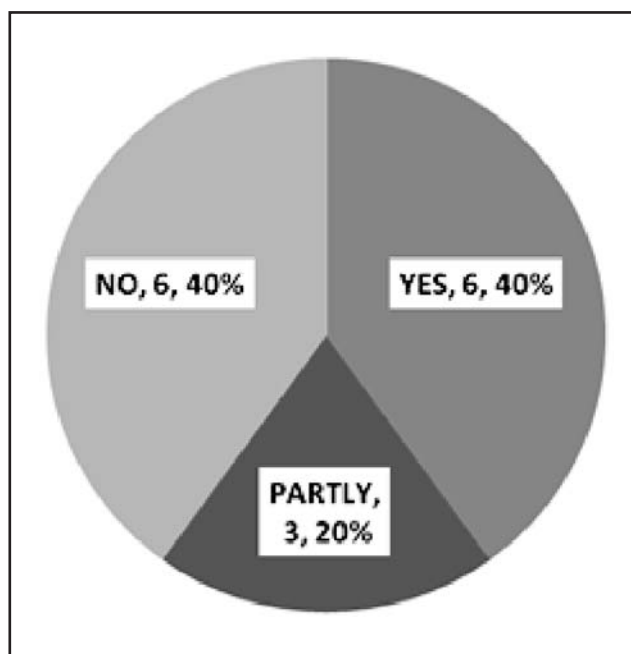


Fig.2: Graphical View of CSO's Responses.

along with their parents and siblings who are expected to provide lifelong supports.

CSOs clearly reflects that development of human resources with emphasis on distance mode along with matching supports are the need of the hour to address the needs of the PWDs as well as to work for its prevention.

PARENTS: Being the primary stakeholders of Child's development, parents (Fig.3) are more committed to get solutions for their concern of '*what will happen to the child after us?*' and reflect that they are very much interested (10 with 67%) to be part of the disability rehabilitation either as professionals or service providers or both. Some respondents (4 with 27%) have expressed their inability in view of their family commitments and others (1 with 6%) are interested to support the cause partly.

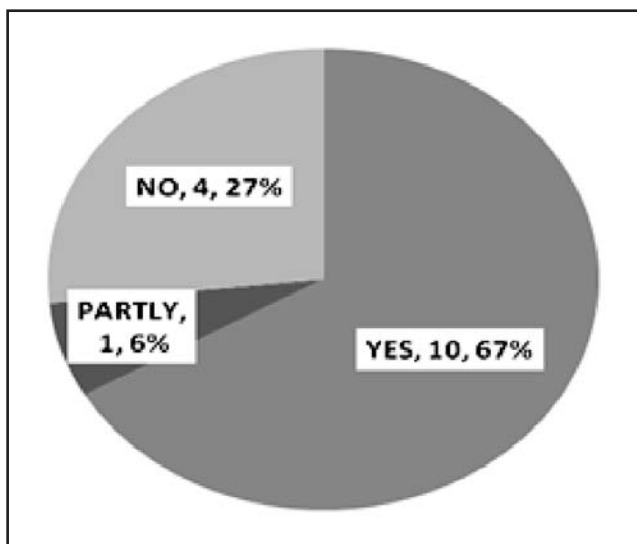


Fig.3: Graphical View of Parent's Responses.

Parents who accept their child's disabilities also believe in their abilities and are committed to be part of the disability rehabilitation including its prevention so that their child will be part of the community development with equality and dignity.

SIBLINGS: This group (Fig.4) accepts that they will be part of the disability rehabilitation either as a professional or service provider or

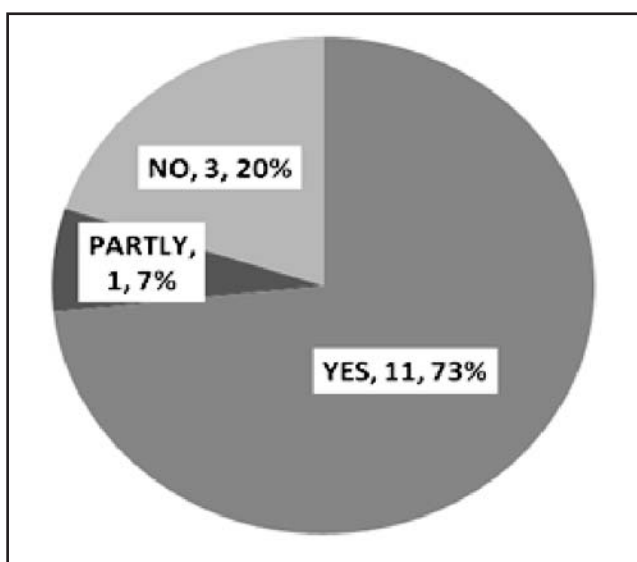


Fig.4: Graphical View of Siblings' Responses.

both (11 with 73%); and among others 3 (20%) support externally and 1 (7%) to be partly respectively.

Siblings who are more concerned with their sibling's development as well as their parent's worries that the child needs special environment with need based supports, are willing to shoulder the responsibility with positive attitude.

PWDs: This group being the primary stakeholders are more concerned about their development along other disability population with equality and dignity in general and in particular the persons with intellectual and developmental disabilities. This group expects that '*nothing about us without us?*' and hope to be the contributing members at all levels to the maximum extent possible in the given environment. Their responses (Fig.5) are very clearly between 'Yes' (12 with 80%) and 'No' (3 with 20%) reflecting their acceptance to be the professionals or service providers or both and possibly external support respectively.

PWDs do have the clarity in moving

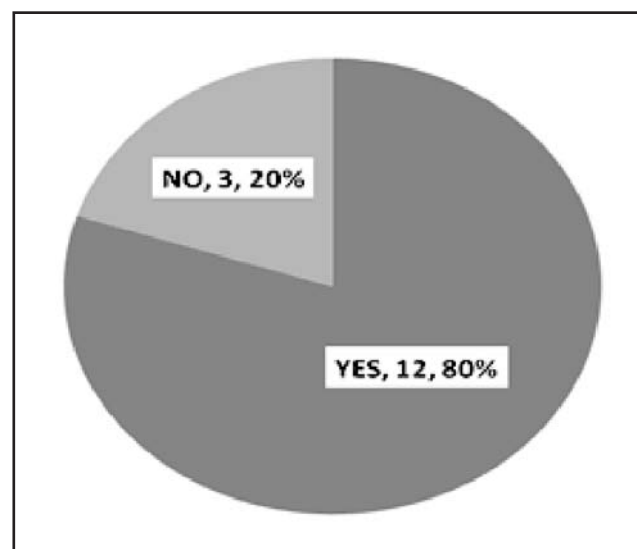


Fig.5: Graphical View of PWD's Responses.

forward with the disability rehabilitation as an empowerment tool for leading improved quality of life (QOL) in an inclusive environment and to answer their parents, concern that *‘what will happen to the child after us?’*.

Cumulative responses of four groups (60 samples with 1,000 responses) have been processed and presented (Fig.6). It reflects that majority (39 with 65%) of the samples are very much interested to work for the empowerment of the disability population with concern and commitment.

Among others, 16 samples (27%) and 5

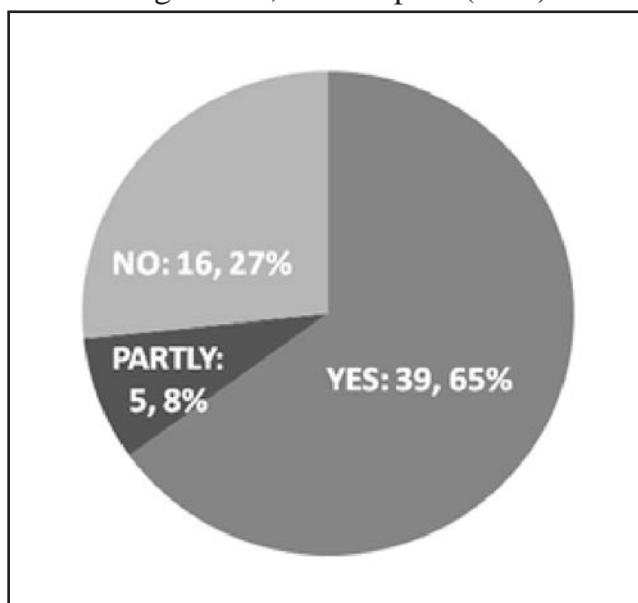


Fig.6: Graphical View of Cumulative Responses.

samples (8%) are ready to extend support from outside and partly interested.

On the whole, the groups clearly reflect the need and concern for the disability population and commitment for their rehabilitation as an empowerment with ethics & values that lead for improved quality of life with equality and dignity.

CSOs will be added strength to the Government with bottom up approaches (BUAs) which are more efficient and effective. Certainly CSOs will have better advantage of 3As in rehabilitation in general and with developing HR in Special Education.

Conclusions

The study made on special area of disability with the key stakeholders has emerged for some conclusions which include:

- ✓ Disability, Poverty and Development are the cause and consequence of each other which further deepens poverty with vulnerability for disability and other challenges;
- ✓ NSSO and Census 2011 indicates updated Disability Population which is alarming;
- ✓ The reach to PWDs is quite discouraging and further become not visible;
- ✓ The PWD Act & NT Act are comprehensive to support Disability Population;
- ✓ MSJ & E, NT, RCI, National Institutes, Universities, and CSOs are playing key role in development human resources in special education;
- ✓ There exists wide gap between availability and demand for human resources which supports for high magnitude of unreached PWDs;
- ✓ The SWOT analysis in respect of Availability, Accessibility and Affordability (3As) indicates the limitations of the special education both on Conventional as well as Distance mode;

- ✓ IGNOU, DR. BRAOU & Study Centres of other Universities run courses in special education on distance mode;
- ✓ The Service Providers / CSOs working for Rehabilitation of PWDs accepts the shortage of HR and ready to run Study Centre for Distance mode of Special Education Courses;
- ✓ Parents have concern with commitment to join DR and to get better solution for their unanswered question that “*what will happen to the child after us?*”;
- ✓ Siblings feel more responsible to support their siblings and parents for better living with security, protection and quality;
- ✓ PWDs being primary stakeholders expect their voice to be heard with concern that “noting about us without us?”;
- ✓ The cumulative responses reflects the strong commitment of the groups to empower the disability population for leading improved quality of life with better ethics and values; and
- ✓ All group accept to:
 - Strengthen environment with better access & mobility;
 - Minimize stigma with better visibility;
 - Strengthen other resources covering machinery, materials and financial support;
 - Strengthen ‘*human resources through distance mode*’ with flexibility;
 - More for right based strategies / interventions with better utility; &
 - Better role for the Parents, Siblings, PWDs & CSOs;

Limitations of the Study

The study does have some limitations in respect of:

- ✗ Group variables like: Age, Gender; Qualification, Location, Experience; Designation; and other such parameters were not considered; and
- ✗ Statistical Software was not used except MS Excel.

Recommendations

The recommendations emerged out of the study includes:

- ✓ In ‘*depth study*’ on each group with all the possible variables including Age, Gender, Qualification, Designation, Experience and Location;
- ✓ Priority needs to be given to Parents and PWDs with better solutions to their concern that “*what will happen to the child after us?*” and “*nothing about us without us?*” respectively;
- ✓ Wide publicity about the Disability Acts & Policies, Prevention, Early Identification, Rehabilitation, Special Education, Schemes, Benefits, and other causes & consequences;
- ✓ Frame better ‘*Recruitment Rules*’ with effective circulation to all the concerned departments;
- ✓ Make Courses ‘*available*’, ‘*accessible*’ and ‘*affordable*’ with support / sponsorships from Governments, private and other agencies;
- ✓ ‘*Encourage*’ CSOs to run Courses in general and particularly in rural areas

both on Conventional & Distance Mode;

- ✓ Develop Special Education as a '*Professional Discipline*' with Research; and

Better '*remuneration*' for Professionals to attract & retain them for better sustainability of Service Providers/CSOs.

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