

TELE-REHABILITATION IS A REALITY TO COME –

A STUDY OF MULTI-LOCATION TELE-REHABILITATION PROJECT “SAMBHAV”

This paper aims
to assess impact of
Tele-rehabilitation project
“Sambhav”
implemented by:
Jan Vikas Samiti, Varanasi,
UP,
on the quality of
rehabilitation services of
partner organizations
and on the life of
Persons with disabilities.

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Executive Summary:

Purpose: Tele-rehabilitation is the clinical application of consultative, preventative, diagnostic, and therapeutic rehabilitation services via two-way interactive telecommunication technology. It is developed to provide reasonable and effective access to quality rehabilitation services at a low cost for people who are physically and economically disadvantaged and living in geographically remote areas. A Project on Tele-rehabilitation titled “Sambhav” was established and implemented by Jan Vikas Samiti with the support from Liliane Fonds in the year 2018 to serve the need for physical rehabilitation in the rural and remote areas of the country. This paper aims to assess impact of Tele-rehabilitation project “Sambhav” on the quality of rehabilitation services of partner organizations and on the life of persons with disabilities.

Method: Data were collected from partner organizations through questionnaire method by a week-long visit to the partner organizations including field visits and by conducting virtual meetings in a few cases. Objective questionnaire, focused group discussion, meetings were also used to collect data for research. The research work has been carried out under the research norms and ethical standards as well as OECD criteria. Questionnaires used has been enclosed with this paper as annexure- A

Results: The study has covered the critical areas of a tele-rehabilitation services. These are Capacity Development, Efficiency, Validity of services and Dependability. These factors will determine the success of any distance mode services and more so tele-rehabilitation services. The average overall efficacy of these factors has been to be 90% which is considered a very encouraging finding.

Conclusions: The recommendations would engage any agency to adopt this model to work on the improvement of the quality to be seen as equal if not more as against the traditional centre-based services. It is an affordable program for remote areas and for poor families in a sustained manner. Expert advice apart, it will enhance the CBR efforts by training the community people in providing home-based services uninterrupted.

Key Words: Tele-rehabilitation, Capacity Development, Validity, Dependability. Home-based services, CBR, and affordable services.

Study Conducted By:

1. Dr. Langoju Govinda Rao. Dr. Rao is Former Director of National Institute for the Mentally Handicapped (NIMH), Secunderabad and National Institute for empowerment of Persons with Multiple Disabilities (NIEPMD), under Ministry of Social Justice & Empowerment, Govt. of India. An XLRI alumnus he has Ph.D., with 40 years of experience in development and corporate sectors involving Delivery of services, Development of Models, Processes, Standards, Projects, Human Resources & Institutions, Discovery of issues, concerns, needs, solutions including innovative and new initiatives, Documentation and Dissemination. In development sector, created value by promoting hundreds of NGOs, Parent Associations and Disabled Persons Organizations (DPOs). He has for the first time introduced software solutions in rehabilitation service delivery and disability certification. Dr. Rao has written many books on Disability Rehabilitation and published research articles in National and International journals.

2. Mr. Debadutta Mishra. Mr. Mishra is a development professional with over 15 years of work experience in the field of social development, disability management and corporate social responsibility with reputed NGOs, Corporate and Govt organizations. Sound academic background and substantial experience in strategy development, policy development, stakeholder management, project management, program implementation, reporting, organizational management, social marketing, development communication and process documentation.

3. Mr. Hiranand. Mr. Hiranand is Project Officer, Jan Vikas Samiti, with extensive experience in disability rehabilitation and has worked in NGOs of national & international repute. He is the technical head and key person behind implementation of Tele-Rehabilitation Project Sambhav. He has trained more than five hundred

professionals & rehabilitation workers in different organizations and developed training modules, manuals, and models in rehabilitation services.

Introduction:

Telemedicine is not new. It began in the 1920s. The current period of rapid growth began almost a decade ago. In four districts of Karnataka between 2012 and 2016 telemedicine system was used to provide medical services to central nervous system-related disorders such as stroke, cerebral palsy, and tubercular meningitis with sequelae or neuromuscular disorders such as Guillain–Barre Syndrome and Duchenne muscular dystrophy. (1) Tele-neurorehabilitation (TNR) is considered as an alternative and innovative approach in health care. It connects the needy patients with the health-care providers with minimum inconvenience and yields cost-effective health care. (2). Telemedicine creates virtual medical collaborative environments. (3) Experiences of the Institute of Vision Rehabilitation, LV Prasad Eye Institute, Hyderabad, prove that the telerehabilitation influenced by the combined efforts of families and therapists is successful in ensuring the continuity of rehabilitation intervention in the prevailing situation. (4) Telerehab has certain challenges to be properly addressed before launching the initiative and those are the scientific, technological, and administrative aspects of implementing. The need for prior training and sufficient experience is to be taken care of. The project should not lose objectivity of the evaluation and treatment while delivering. (5).

In consideration of the need for rehabilitation services, the project of telerehabilitation service delivery has been taken up by Jan Vikas Samiti. The objective of the project is to give the best benefit to the end-user (i.e., an individual with a disability) within their environment. It should optimize the timing, intensity and duration of therapy that is often not possible within the constraints of face-to-face treatment protocols in current health systems.

From the inception of the program in mid-2018 to May 2020 more than 650 children with disabilities are assessed and their rehabilitation plan has been made in the pilot phase. PO heads and field staff have shared that they are now able to provide

quality intervention in remote areas as per the physical rehabilitation protocol through tele-rehabilitation.

An in-depth evaluation has been undertaken to assess the extent to which the telerehabilitation project Sambhav has started bringing about anticipated changes, to examine which factors have proved critical in helping or hindering change and draw lessons for future programming. The focus on learning does not reduce but rather increases the need for doing evaluations in the right way by following the right steps and procedures. One of our key principles for evaluations is they are not driven by accountability purposes, focus on learning and deliver concrete validated recommendations that can be implemented within a reasonable timeframe.

The research paper deals with the process of the evaluation and its analyses to arrive at learning of the lessons for further improvement and finetuning of the future initiative and spreading of telerehabilitation in other parts of the country. It can also serve the purpose of a model to be adopted.

The research study has covered the appropriateness of the methodology, the process of evaluation, the constraints and challenges in implementing of the Project - Sambhav. What lessons can be taken away by the Project Sambhav that can give direction to future projects. This will also help in developing the training model and materials.

Review of Literature:

1. Telerehabilitation: Review of the State of the Art and Areas of Application

Reviewed by: Kevin Yap, Silvio Penteado, Goran Petersson, Sandra Morelli, and Line Lundvoll Nilsen, Ref: <https://www.ncbi.nlm.nih.gov/>

In the last few years, telemedicine applications have been increasing due to the development of new computer science technologies and of more advanced telemedical devices. Long-distance communication can be easily achieved by videoconferencing, email, and texting, to name a few. Today there is the possibility of controlling robots, robotic arms, or drones at a distance. Thanks to these advancements, the course of human action has been considerably transformed. During the last 20 years, demographic changes and increased budget allocation in

public health have improved new rehabilitative practices. Rehabilitation is an old branch of medicine, but in the last few years, new tele-communication-based practices have been developed all over the world. These approaches in the field of rehabilitation are commonly defined as telerehabilitation, which should be considered as a telemedicine subfield consisting of a system to control rehabilitation at a distance. Telerehabilitation has been developed to take care of inpatients, transferring them home after the acute phase of a disease to reduce patient hospitalization times and costs to both patients and health care providers. Telerehabilitation allows for treatment of the acute phase of diseases by substituting the traditional face-to-face approach in the patient-rehabilitator interaction. Finally, it can cover situations in which it is complicated for patients to reach traditional rehabilitation infrastructures located far away from where they live. Controlled studies on rehabilitation have demonstrated that quick management of an injury or a disease is critical to achieve satisfactory results in terms of increasing a patient’s self-efficacy. Hence, a rehabilitation program should start as soon as possible, be as intensive as possible, be prolonged, and continue during the recovery phase. A major factor is the initiation time, which, in general, should begin as soon as possible. In most cases, the initial stages of rehabilitation, after the occurrence of a disease or injury, could be performed by patients at home even if they need accurate and intensive treatment. For these reasons, telerehabilitation was developed to achieve the same results as would be achieved by the normal rehabilitation process at a hospital or face to face with a physiotherapist. Various types of telerehabilitation treatments and their relative intensities and duration have been reported. The first scientific publication on telerehabilitation is dated 1998 and, in the last few years, the number of articles on the topic has increased, probably because of the emerging needs of people and due to the development of exciting new communication and computer technologies.

2. Ten Years of Tele-Rehabilitation: A literature overview of Technologies and Clinical Applications.

Reviewed by: Marco Rogante, Mauro Grigioni, Daniele Cordella, Claudia Giacomozzi. Ref: <https://pubmed.ncbi.nlm.nih.gov/>

The authors have reviewed the literature by analysing the entire set of articles under the search terms "telerehabilitation" or "tele-rehabilitation" to portray "state of the art" ten years after the publication of the first scientific article on the topic. A structured study has been conducted by considering all those articles containing the word "telerehabilitation" or "tele-rehabilitation". Medline, Embase, Cochrane, UK Centre for Reviews and Dissemination, Canadian Agency for Drugs and Technologies in Health databases have been interrogated for articles between 1998 and 2008. 146 scientific articles were found. 56 articles focus on patient treatment, 23 are reviews, 3 are to be considered as both patient treatment papers and reviews, 53 are either technical reports, system descriptions or analyses of new approaches; 8 are general discussion on telerehabilitation. The present paper draws the scenario of the first ten years of telerehabilitation, focussing on clinical applications and technologies. Basically, it confirms the lack of comprehensive studies providing evidence for supporting decision and policy-makers in adopting telerehabilitation technologies in the clinical practice. An overall lack of standardisation in the used terminology also results from the analysis of keywords, which is typical of quite recent fields of application.

3. Evidence of Benefit From Tele-Rehabilitation In Routine Care: A

Systematic Review

Reviewed by: David Hailey, Risto Roine, Liz Dennet

The authors have systematically reviewed the evidence on the effectiveness of telerehabilitation (TR) applications. The review included reports on rehabilitation for any disability, other than mental health conditions, and drug or alcohol addiction. All forms of telecommunications technology for TR and all types of study design were considered. Study quality was assessed using an approach that considered both study performance and study design. Judgements were made on whether each TR application had been successful, whether reported outcomes were clinically

significant, and whether further data were needed to establish the application as suitable for routine use. Sixty-one scientifically credible studies that reported patient outcomes or administrative changes were identified through computerized literature searches on five databases. Twelve clinical categories were covered by the studies. Those dealing with cardiac or neurological rehabilitation were the most numerous. Thirty-one of the studies (51%) were of high or good quality. Study results showed that 71% of the TR applications were successful, 18% were unsuccessful and for 11% the status was unclear. The reported outcomes for 51% of the applications appeared to be clinically significant. Poorer-quality studies tended to have worse outcomes than those from high- or good-quality studies. We judged that further study was required for 62% of the TR applications and desirable for 23%. TR shows promise in many fields, but compelling evidence of benefit and of impact on routine rehabilitation programmes is still limited. There is a need for more detailed, better-quality studies and for studies on the use of TR in routine care.

Methodology:

The study brings together information from evaluation report and data collected from partner organizations through questionnaire method by a week-long visit to JVS Head quarter as well as the partner organizations including field visits and by conducting virtual meetings in a few cases. Case study method has also been adopted to find out the efficacy of the program. Objective questionnaire, focused group discussion, meetings were also used to collect data for research. A written questionnaire was sent to the partner organizations by email and were asked to fill up by the staff coordinating the Tele-Rehabilitation project. The questionnaire focused on implementation of suitable rehabilitation therapy and their impact on the clients. The responses were also received through email or in the form of hard copies by hand, through physical visit to the JVS head quarter. This phase was followed by focused group discussion and meeting with rehabilitation staffs in partner organizations. In addition, semi-structured interviews with clients and parents to understand their perceptions regarding the tele-rehabilitation services. The research work has been

carried out under the research norms and ethical standards as well as OECD criteria. Questionnaires used have been enclosed with this paper as annexure- A

Implementation Process:

Tele Rehabilitation Project “Sambhav” is directly implemented by Jan Vikas Samiti (JVS), which is a community development organization based in Varanasi (UP), India, and working for poor and marginalized sections of society since more than 25 years. The organization has a good presence at grassroots with over 850 SHGs, animated by a team of 60 committed professionals, social workers and volunteers, who ensure an effective reach of its programmes to the people with ‘last mile connectivity’. The Tele-rehabilitation project “Sambhav” is implemented under the Disability Inclusive Programmes of JVS, which has been recognized by the Department of Persons with Disabilities, Govt. of Uttar Pradesh, and has been conferred us with ‘State Award for Empowerment of Persons with Disabilities – 2020’. The “Project Sambhav has bagged the ‘ZERO Project Award – 2022. The overall goal of the project is to improve the quality of physical rehabilitation of children and youngsters with developmental disabilities in the north and northeast region of the country. For achieving this, it has several objectives, such as developing a protocol for the rehabilitation diagnosis/planning of children with developmental disabilities, developing a tele-rehabilitation unit at JVS and by providing inputs to the CBR workers/rehabilitation professionals. Specifically, the project aims to capacitate CBR facilitators on rehabilitation diagnosis, making custom made treatment/rehabilitation plans and providing appropriate therapies to the children and youth with disabilities who are most in need in the rural parts of India. Additionally, capacities of the partner organizations and sub-centres were enhanced on physical rehabilitation of children with developmental disabilities through the tele-rehabilitation unit at JVS.

The project followed three modes of implementation, mirrored in the three outputs

- (1) A Protocol for the rehabilitation diagnosis/planning of children with developmental disabilities will be made in the headquarter of Jan Vikas Samiti (JVS).
- (2) Development of toolkits for Baseline survey forms, Assessment form for children with disabilities.
- (3) Capacity building of CBR workers of partner organizations for Tele-rehabilitation service delivery provision.

Partner Organizations, Respondents & Dates of Visit.

S.N.	Name of Organisations & Address	Name of the Participant	Date of Visit
1.	AGRA CATHOLIC DIOCESE SAMAJ SEVA SANSTHA, UP	Fr. Sibin	23-02-2022 Physical Visit
2.	BETHANY SOCIETY, MEGHALAYA	Response Could not be received	23-02-2022 Virtual
3.	DIOCESE OF VARANASI SOCIAL WELFARE SOCIETY, UP	Fr. Julian	23-02-2022 Physical Visit
4.	FAKIRANA SISTERS SOCIETY, BIHAR	Sr. Saroj/ Mr. Amit Kumar	22-02-2022 Physical Visit
5.	FRANSISCAN CLARIST SOCIETY OF NORTH EAST, ASSAM	Response Could not be received	22-02-2022 Virtual
6.	GRAM CHETNA KENDRA, RAJASTHAN,	Mr.Om Prakash Sharma	22-02-2022 Virtual
7.	HD FOUNDATION, MANIPUR	Response Could not be received	22-02-2022 Virtual
8.	HOLY CROSS WELFARE TRUST, UP	Sr. Reshmi/ Mr. Rajendra Prasad	24-02-2022 Physical visit
9.	PATNA NOTRE DAME SISTERS SOCIETY, BIHAR	Sr. Anupama/ Mr. Niranjana/ Mr. Krishna	24-02-2022 Physical Visit
10.	NIRMALA SADAN SOCIETY, UTTARAKHAND	Sr. Sunita Toppo/ Ms. Arshi	24-02-2022 Physical Visit
11.	SACRED HEART SISTERS TRAINING SCHOOL, BIHAR	Sr. Ambrose/ Mr. Vishal Victor	22-02-2022 Physical Visit
12.	ST. PAUL SERVICE SOCIETY, MADHYA PRADESH	Sr. Regi Paul and Sr. Bincy/ Mr. Bansilal	22-02-2022 Virtual
13.	THE KODERMA FRANSISCAN CLARIST SISTERS, JHARKHAND	Sr. Leelajosh/ Mr. Jaimangal Sahi	21-02-2022 Physical Visit

14.	THE SISTERS OF ST CHARLES SOCIETY, BIHAR	Sr. Anne/ Sr. Pushpa	24-02-2022 Physical Visit
15.	NJKSS, CHHATTISGARH	Mr. D.R. Jyoti/ Mr. Ramsnehi	24-02-2022 Virtual
16.	RARE, ODISHA	Mr. Ananga Negi	26-02-2022 Physical Visit
17.	JVS SUB-CENTER, BIHAR	Fr. Akshay/ Mr. Premprakash	23-02-2022 Physical Visit

State wise distribution of Partner organizations:

1. Uttar Pradesh	...	3
2. Bihar	...	5
3. Jharkhand	...	1
4. Odisha	...	1
5. Madhya Pradesh	...	1
6. Chhattisgarh	...	1
7. Rajasthan	...	1
8. Uttara Khand	...	1
9. Assam	...	1
10. Meghalaya	...	1
11. Manipur	...	1

Physical visit ... 11 POs

Virtual study: ... 06 POs

Dates/duration of visits: 21st to 26th February 2022.

Responses: (Number of responses received =14)

Sl. No.	Questionnaire	Number of Responses	
		Yes	No
	Capacity Development		
1.	Is the tele-rehab unit at JVS functional fully as per the schedule?	14	0
2.	Are the CBR facilitators on rehabilitation diagnosis adequately trained?	14	0

3.	Was the capacity development of Partner Organizations and sub-centres in providing physical rehabilitation fully effective and completed by end of 2020?	5	9
	Overall 42 total score for Capacity Development and 33 of 42 = 76%		21%
	Efficiency		
4.	Is the tele-rehab solution user friendly?	14	0
5.	Are there any bottlenecks in the functioning of tele-rehab system? No is a positive response. Hence counted.	0	14 +
6.	Have they brought bottlenecks to the notice of the specialists? 57% of respondents escalated bottlenecks = 8 of 14 – Individual item % (Not to be counted for efficiency.)	08	0
7.	Is the tele-rehab capable of diagnosing correctly all the time?	12	0
8.	Are there any occasions when the diagnosis was not right? (“No” is positive response.) Individual % = 2 of 14 = 14% “Yes” is a Negative score	2 (-) (14%)	12 +
9.	Do you find the therapy not appropriate at times? 14 Yes is negative value Hence not taken, as it was not there originally	14 +	0
10.	Was the Project SAMBHAV found as reliable e-rehab system?	14	0
11.	Is the Project SAMBHAV better than the traditional physical rehabilitation in terms of efficacy?	12	2
	Only positive responses are taken into account = 6 items = 78 of 84 = 93%. So there is a deficit of 7% in efficiency, which needs to be taken care of.		
	Dependability		
12.	Is the Project SAMBHAV better than the traditional physical rehabilitation in terms of confidence and capability generated in the parents to be the care-givers at home? (Dependability)	12	2
13.	Do you strongly recommend the Project SAMBHAV to be introduced in the rural areas in other States, regions, and districts? (Dependability)	14	0
	93% positive score = 26 against 28 overall		
	Overall Average = 137 out of 154 = 89%		

1. Capacity Development = 33 out of 42 = 76%
2. Efficiency = 78 out of 84 = 93%
3. Dependability = 26 out of 28 = 93%
4. Overall Rating = 137 out of 154 = 89%

Analysis of the responses:

In all, thirteen questions were asked to assess the viability and efficacy of the project implementation. It was also intended to identify the grey areas so that improvement plan can be drawn for future projects. Overall, the feedback was found to be satisfactory with 12% negative response. There are, however, two important

aspects that need to be improved – Capacity Development and Efficiency. Of course, both are inter-related. Detailed analysis, to pin-point the weak areas was done. The questions have been asked broadly from four major areas and the findings are mentioned below:

1. Capacity development: Except for providing physical rehabilitation, which received a negative response of 64%, the other two aspects had 100% positive response. This is a fact that the rehabilitation intervention has been designed to be of distance mode through tele-rehabilitation, and, therefore, there has been not adequate physical rehabilitation. The partner organizations need to be adequately trained so that they can include physical rehabilitation services wherever necessary to the satisfaction of the parents. However, taking the clue from the feedback, the next phase can plan the physical rehabilitation in a limited manner to instil confidence and motivation among the persons with disabilities. Capacity development is adequate except for physical rehabilitation services at a regular interval for the purposes as suggested above. The average positive response for this aspect is 76%. Focussing on the aspect of physical rehabilitation is needed.
2. Efficiency: The vital aspect of escalating the bottlenecks had some degree of negative response of 43% that can be answered by having a structured feedback system during the implementation of the program. The other two questions had 100% positive response that indicates that there was good efficiency in the delivery of tele-rehabilitation services. The overall positive rating is 93%.
3. Validity: Appropriateness of the therapy was perceived to be lacking as responded by 14% of the sample. Similarly, 14% of the respondents found the telerehabilitation not better than the traditional method. These two aspects are very critical in the ultimate success of the tele-rehabilitation. A further study in detail of these two aspects is needed also involving the stakeholders.

However, the overall average negative response is only 6% and this is obviously indicative of the project being successful.

4. **Dependability:** An average of 7% of the responses was reported to be negative which is negligible. It is about the comparison between traditional and tele-rehabilitation. In the ‘Validity’ area also, the same point received not all that positiveness. This aspect must receive focussed attention to bring improvement as suggested above.

Qualitative findings:

The research study has undertaken five case studies of different types of disability from various regions. The analysis of these cases had been done and the findings are as under:

1. A 12-year girl with C.P. Diplegia belonging to poor family with very restricted mobility and totally dependent for ADL, from Jharkhand did not get the benefit of the professional rehabilitation services till she was enrolled by the Project staff in July 2019. During these months the centre has provided good care of her ADL activities and rendered required physiotherapeutic interventions. With the provision of KAFO and good cooperation and efforts on her part, it has been observed her to be independent in mobility and attending to most of ADL successfully.
2. A 3-year boy having CP quadriplegia from remote Bihar was attended to by professionals and advised physiotherapy interventions and other rehabilitation measures, but being in a remote area, the parents found to be expensive for availing services from far off centre. Tele-rehabilitation services helped the boy to a great extent.
 - Able to stand with support and tries to take some steps forward
 - Tightness in upper limbs and lower limbs are reduced
 - Able to hold the objects with hands
 - Do shake hand, ta-ta and goodbye
 - Able to speak the few familiar words
 - Play with other children in home

3. A 5-year boy with Cerebral Palsy Diplegia, from Jharkhand, having difficulty to put both the legs parallel on the ground and difficulty in walking. His father a teacher by service had provided rehabilitation services but it was difficult for him to sustain to avail rehab services from far off places. Though initially he was reluctant to enrol with Sambhav project, with vigorous persuasion, the boy was provided the tele-rehabilitation services. Now the progress is:
 - Keep his legs down,
 - Able to stand up,
 - Slowly moving around,
 - Speaking and reading,
 - Tightness of the body getting reduced.
4. A 7-year girl having developmental disability, unable to sit, stand and walk, and having drooling with saliva, not able to speak and ADL dependent, from Betiya, Bihar was enrolled in Sambhav. She received home-based therapy by her mother was trained in the basic therapy like proper positioning and stretching exercises. Her condition has improved. The excessive salivation is reduced, improvement in co-ordination in hands while handling objects, she can sit without support and able to stand with support.
5. A 6-year boy Cerebral palsy Quadriplegia from Bihar has been enrolled in Sambhav. With right kind of rehabilitation services, now the boy has improved a lot. He now holds things, takes food by his own hands, stands, walks, speaks and freely mingles with others.

The findings of these case studies indicate that with the right kind of rehabilitation interventions, provision of aids and appliance and continuous therapy, there will be considerable improvement and the children have overcome the dependence of ADL, able to move, speak and interact besides reading. It is proven that the tele-rehabilitation is successful and achieved the set objectives.

Challenges:

- i. Diverse Geographical location of all partner organization (POs) was a challenge to visit physically and observe the implementation of projects for study. So, data has been collected through conducting virtual meetings with few POs.
- ii. Diverse age group and nature of disabilities of the clients was also a challenge for quantifying the impact or findings.

Recommendations:

1. The tele-rehabilitation with some improvement as suggested in the analysis is a very good home-based model to reach the communities in the rural area and far-flung areas lacking required facilities.
2. It is a boon for the families that cannot afford centre-based services.
3. It is a very suitable model for CBR programs.
4. Parents and local community people can be trained to provide regular therapy assistance at home.

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