RURAL POLIO DISABLED – REACHING UNREACHED THROUGH COMMUNITY BASED REHABILITATION : AN ALTERNATIVE STRATEGY IN PLACE OF CAMP APPROACH

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Community based rehabilitation as a concept, a decentralised process having economically realistic approach towards comprehensive integrated rehabilitation of the disabled. Low cost caliper designed and developed at our centre has given encouraging response to the Polio affective children.

WHO estimated that there are about 120 million people with disabilities in the World, who require rehabilitation services. Only 2-3 million received some form of rehabilitation. Rehabilitation services are at present grossly insufficient especially in the developing countries. The existing urban based institution are able to reach only a minimal proportion of the disabled, probably some 2-5% of them in the developing world. Extension of traditional pattern of services in the near future is beyond the means of most of the countries due to financial, technical and manpower constraints. It is therefore not possible to provide rehabilitation services to all in need, unless the services are decentralised, becomes community based and integrated with general services in the area of health, education, employment and social facilities.

CBR as a concept, a decentralised process having economically realistic approach towards comprehensive integrated rehabilitation of the disabled. According to Dr. E. Holender, chief of Rehabilitation, WHO, the future of Rehabilitation lies in understanding that rehabilitation gap can be closed if the following is recognised –

1. CBR is a most realistic approach and its success relies on the willingness of the communities to provide the necessary local resources.
2. National Governments must be fully committed to the community based services.
3. The main constraints is the lack of adequately trained community workers.
4. There is also lack of coordination among the donor organization in the developing countries.

Now the question is how to provide essential rehabilitation services within the context of community services and to integrate rehabilitation and disability prevention into the existing health delivery system and other relevant sectors. Krol (1982) has attempted to answer these questions based on the following principles :

1. To provide essential rehabilitation services using the Primary health care approach, thus using the community level action rather then highly sophisticated institutions.
2. To encourage participation of the community and in particulars to involve families/disabled in the rehabilitation process.
3. To promote use of approaches and technologies which are feasible, affordable and appropriate to local environment.

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4. To develop community based infra-structure for supervision, training and referral, using existing health and related general services.

During 16th World Congress of Rehabilitation International held at Tokyo, Japan during September, 1988, where 5 case studies on CBR projects from Nepal, Sri Lanka, Kenya, India and Thailand were presented. A noticeable point in 5 CBR was that each project in some way unique in its structure, responding to needs or resources of different countries and communities.

The common element in all was the family. A number of points of general interest emerged from the discussions on the CBR.

- Persons with disabilities must organise themselves with the active involvement of their families and their communities.
- Transfer of knowledge and technology must take place on a massive scale if CBR is to succeed.
- A caring relationship must be established between disabled person and the community.
- Active links must be forged with the primary health care system.
- CBR cannot succeed without an active link to the community development process.
- Confidence and trust of the communities is critical for the work of a CBR worker.
- Negative attitudes are the biggest constraint facing and CBR programme.
- The importance of on-going training and good professional back up support cannot be overstated especially during early stage of project.
- NGO's act as innovating agents to set up CBR which are later proceed on the government for large scale application.
- There is shortage of trained personnel, lack of supervisors, scarcity of models, & lack of planners due to which progress is stand still.

Patience and persistent work is needed to produce results.

In order to reach families with disabled polio children with useful information which will benefit the child and the entire family, a programme of information collection and dissemination has to be launched at National & State level. Appropriate materials, providing practical information on disability prevention to parents and the community at large are needed for a successful CBR programme.

Appropriate Technology & CBR

The role of technology in prevention, early detection and rehabilitation is unquestioned and there is no doubt that technology helps the disabled person in gaining increased independence, mobility and ambulation access to employment, improved communication ability and improved quality of life as a whole. In his key note address during World Gongress of R.I., Dr. Ramalingaswami, said, Technology must preserve and enhance human dignity.

There are many devices being developed today to assist persons who are physically disabled to lead normal and independent living. These relate to feeding, toiletry, reading, recreation, and transportation. Appropriate technology is most relevant to CBR. Fortunately, by now, it has been realised that appropriate technology is not inferior technology but it is a technology that utilises local material, skill and it is firmly based on scientific principles. The light weight wheel chairs, which can be easily used on village road, sturdy, and based on simple technology has been developed. Similarily, Low cost Calipers for polio effected children have been developed which is not only affordable and simple but can be prepared by minimal skills in village settings. Jaipur foot and metal prosthesis is another examples of work done in the field of appropriate technology. The development of a low cost hearing aid that could be mass produced for the developing countries has also been reported.

Model of community Rehabilitation :

A three-tier model has been designed based on primary health care system with provision of interaction with other sectors related to disability (Krol, 1982).

1. Basic community level
2. Intermediate support

3. Specialized services.

Basic Community Level :

BCL is made of the families of disabled persons, local community Rehab. workers, general community services and specific community infrastructure. This is so designed to provide essential rehabilitation services in local environment, at home and immediate surroundings of the disabled persons. The family needs motivation, interaction and support, to be provided by community rehabilitation worker. He can be a local primary health care worker, teacher, social worker or any other community worker who is willing and able to undertake the task and has been given some simple training to this effect.

The duties of CRW will also be, in addition to motivation, training and direct supervision of the family/disable, to identify the disabled, assess or refer for assessment counsel and follow up instructions from the referral level. Existing local infrastructure and general community services like community development, health, nutrition, education, employment and social facilities constitute important element of support to the family in its rehabilitation tasks.

Intermediate support (I.S.)

I.S. gets help mainly from existing facilities and personal from the general health services like primary health care Centre, district hospital. I.S. has to take use of other general services like education, training/employment, social welfare which are available at district level.

Medical and para medical staff like nurses, midwives, social workers & teachers etc. who are available at this level must be given orientation and appropriate training in the field of disability, to enable them to train and supervise the local CRW and provide first referral level services.

In the long run, a multipurpose rehab. worker is needed at this level who should act as a local team member to take care of the Community Programme, Planning and Management.

Specialised Services :

The Apex of the model is made up of specialised services including medical rehabilitation, special education, vocational and social rehabilitation in addition to their usual tasks of specialised service delivery, training of manpower, research and development. They should be oriented to stimulate development, of Community programmes, give support to and complement the whole CBR. They are most precious expertise resource to the CBR.

Specialised rehabilitation services do exist in almost all countries, but the basic community level services and intermediate support do not exist as part of the operational Rehabilitation scheme.

The Disability Situation in India in Relation to Polio

More then fifty percent of Orthopaedic disability in rural India is due to Poliomyelitis. A rough estimate puts 200.000 cases of Polio are added every year. (Rama Lingaswami, 1983). In a study at R.A.L.C., K.G. Medical College, Lucknow during 1987, we have observed that out of 3624 cases of childhood disability, 2134 cases were due to poliomyelitis (58%). In our experience of nearly thirty rural camps, in the past several years (1972-1990) more then two third disabled cases were of Poliomyelitis.

Appliances for Poliomyelitis :

Since Poliomyelitis is the single largest cause of physical disbility in our country and it has practically disappeared from west, hence not new ideas are coming from abroad on designs of appliances for Poliomyelitis. Therefore we have to generate new thinking in the whole situation. We have been using conventional metal calipers over decades, but any sincere fellowup would reveal that there are large number of such cases who do not use the calipers after taking the delivery from the hospitals. Dr. P.K. Sethi in his prestigious lecture delivered on 16th Jan., 1989 at Indian National Science Academy, had analysed the situation of designing aids for Poliomyelitis as suited to rural India. His philosphy and thoughts are quite relevent to our present day. According to him, three different kinds of options are available for aids in Poliomylitis. One is to continue with the present strategy of a centralised production agency, supplying factory made metal components, to be assembled and fitted locally. It does not permit any change in design and needs a large beaurocratic machinery to manage the supply and fitting. Second is to continue research into the use of new material and design and field test them. It requires a much of R & D efforts, specially multicentre study in our vast country. Third is to simplify the existing designs and work out a strategy of using rural craftsmen and local material to provide a community based facility.

The cost and benefit of each will have to be worked out. Keeping in view the user who would remain and belong to group of rural poor.

Present Day Situation of Appliances :

An analysis of the reasons for long waiting list in the delivery of calipers in most rehabilitation centres, reveal that the major hold up occurs in the foot-wear section. In practice, the shortage of good skilled workers add to the problem. The idea of subsituting shoes with wooden clogs as initially started by Huckstep in Uganda has many drawbacks. Hence more hard work has to be put to redesign the clog which allow better gait. This wooden clog can be made easily and with pre-fabricated leather straps and uprights of different sizes, it is feasible to fit the child on the same day. Every village has a cobbler, carpenter and a blacksmith who are needed by rural community. Their innovative skill and capacity can be very well utilized in making their own version of a caliper.

Low cost calipers thus developed at RALC, Lucknow had the simillar experience i.e. shoes were replaced by tyre sole sandles made by roadside semi urban people who are catering the needs of poor since ages. The uprights were also made out-side of RALC by semi skilled persons. Both were assembled and delivered to Polio child on the same day. We have fitted more then 500 such calipers. The initial response was encouraging.

RURAL POLIO CAMPS : PRESENT & PAST

We have experience of large number of Rural disabled camps in last two decades where a large number of polio came with hopes & expectations out of which in atleast 20% to 30% cases, the deformities are such, which can not be corrected hence the mobility aids like tricycle, wheelchair are the only answer. In remaining cases nearly 40 to 50% will require reconstructive surgery before we can fit proper caliper to them. Therefore only a small percentage of cases are available for the measurements of the calipers. We have under taken even three stage camps where we were able to satisfy only a small percentage of Polio victims. We have a feeling through camps an awareness creeps in the local area, where people came in large number. The philanthropic and service organisation provide services during the tenure of their office holding which, they tend to forget as the time passes. The question of followup does not arise in these situations. In view of these observations, which will be shared by all, who are involved in the disabled welfare programme or who have participated in such camps will like to share with us that camp approach for the rural areas provide the benefit in other spheres like catract surgery, medical checkup and immunisation etc. However in case of Polio affected children and adults only some of them can be benefitted by providing some mobility aid on the spot, provided the supplies have been adequately procurred before hand. There is no doubt regarding the awareness it generates among the masses which is not available at the moment. The demand of rural population can only be met by taking the programme to the grass root level & with active participation of the community.

D.R.C. Programme of Rural Polio Affected Disabled

Ministry of Welfare, Government of India, has envisaged a pilot project in India through which 12 District Rehabilitation Centres have been opened in different parts of country to provide all the facility to rural physically disabled. It includes identification, registration and individual detailed assessment of the disability where polio victims are also included. DRC Scheme provides medical, para-medical & technical expertise. It also provides an opportunity to the local community for its active and meaningful participation in the programme.

It has further scope of redesigning the calipers and other mobility aids which suits to our socio-cultural environment. Although the existing model of DRC has been revised due to financial constraints. However, the present and modified module further require critical assessment and evaluation so that the services can be made more effective and strengthened. DRC scheme requires much more coordinated efforts with the existing health delivery system and with integrated child development schemes to avoid duplication of the services and to provide better utilisation of existing services. This will really streamline the project and inturn it will reach to target group.

The future plan of opening of 100 new DRC in the eighth five year plan, will provide services to the atleast one fourth of the population of India in

phased manner. The success of Rehabilitation programme of Rural Polio disabled will depend on the following :–

1. Effective immunisation programme in general and rural areas in particular.
2. Generation of awareness in the rural areas regarding facilities available to the rural polio affected children.
3. Effective service delivery system through DRC Scheme.
4. Provision of Integrated Education for disabled children.
5. Vocational training and placement to the disabled though various rural based schemes of employment.

N.G.O's & Rural Polio Disabled :

As we all agree that no government programme can be successfully implemented without the participation of the people. The probelm of Polio disabled in our vast country is so big and complex that we can not overlook the role of N.G.O's in our overall endeavour. Government is encouraging N.G.O's in the field of rehabilitation of disabled by providing financial assistance and other technical help through National Institutes & Regional Rehabilitation t raining centres etc. Now the time has come, we ourself, should encourage atleast one N.G.O. in each district. This will help in active participation and service delivery at periphery. They must come forward and generate their own resources for the noble cause. We can look forward to big industrialists, public sector undertakings, financial institutions to adopt at least one block of one district for rendering the social service through the existing infra-structure of DRC scheme.

Government & Rural Polio Disabled

We look forward to Government of India for liberal welfare measures including tax benefit for such work, which will provide the incentive to the big houses for investment. Although there is exemptions for such donations to N.G.O's who are under taking these programmes. Similarly more funds can be very well invested by Non Resident Indians (N.R.I.) if Government provides some incentives to them. We feel there should be no financial constraints if Government & public sectors have will and a desire to pour their funds which will add to the per capita income of these disabled, the prosperity thus gained will not only make them independent but country will feel proud of them.

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