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CAPACITY BUILDING IN THE REHABILITATION OF THE MENTALLY ILL TOWARDS INCLUSION.

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Abstract

Social exclusion is a major barrier in disability rehabilitation and care. However capacity building can overcome those barriers and redirect disability rehabilitation as an inclusive model.

This study is an attempt to explore the multiple capacity building programme practiced in nearly 90 centres in Kerala where the destitute mentally ill persons are cared and rehabilitated through individual initiatives. The objective of the study is to explore different capacity building programme tried and succeeded in the rehabilitation of the mentally ill in the past 20 years or more. A qualitative research design was used in which case study methodology was adopted to find those capacity building models. The study result shows that capacity building among the mentally ill could be implemented through a humanitarian and familial approach. Participatory method was highly effective in capacity building. Engaging them in day to day functioning, providing responsibilities and validating their services, respecting their minute needs and helping them to cope up the illness, spiritual and emotional support and mobilizing community support are a few methods of several capacity enhancement programme in such centres. It is a right based approach and highly promotive and functional. Systemic and structural theories are substantiating this process model.

International attention is brought to this model through World Association for Psycho Social Rehabilitation.

Introduction:-

Mental health is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. WHO estimated that globally over 450 million people suffer from mental disorders and in India there are 30 million people suffering from different types of mental illness. Most of the mentally ill persons are cared at home by the family members while a few are in government run rehabilitation centres and others in private rehabilitation centres. Indian streets are not free from wandering mentally ill people and the family based rehabilitation practices initiated by

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different individuals in the state of Kerala and other states in India is an innovative step in the care and rehabilitation of the mentally ill persons.

This paper is based on the study conducted in such centres where the capacity building of the inmates take a new turn with high rate of rehabilitation and better recovery outcomes. It could be a family based community rehabilitation of the mentally disabled worked out from less professional background and leading challenging questions to the existing professional dimensions in the rehabilitation of the mentally disabled. A brief review of the literature is made to set the background for the theme of capacity building under research.

Challenges in mental health rehabilitation:-

Analysing the epidemiological factors of mental health will help to fix the challenges of rehabilitation of persons with mental illness. Currently mental and behavioural disorders account for about 12 percent of the global burden of diseases. This is likely to increase to 15 percent by 2020. Major proportions of mental disorders come from low and middle income countries (WHO, 2001).

A study conducted in Pune in 2012 reported the overall life time prevalence of mental disorders to be nearly 5 percent. Males were reported to be at higher risk. Major cause was depression followed by substance abuse and panic disorders (Deswal et al, 2012). These findings were similar to results of the meta-analysis, which estimated the prevalence of mental disorders to be 5.8 percent among the Indian population (Reddy et al, 1998). In 2010, a study conducted in NIMHANS, Bangalore reported that the burden of mental and behavioural disorders ranged from 9.5 to 102 per 1000 population. Reason behind such a wide range of prevalence could be that few studies had focused on isolated settings (Math et al, 2010).

As regards methods to address the burden of mental illness family groups had a major role. A study on MARGADARSI and AMAND, two Self Help Groups of the care givers of mentally ill person showed that the burden of caregiving could be reduced through organised family support systems, ongoing capacity building programmes by support groups and networking of such agencies with mental health delivery institutions like hospitals (Prince et al, 2005).

Most strongly associated factors with mental disorders are deprivation and poverty. Individuals with lower levels of education, low household income, lack of access to basic amenities are at high risk of mental disorder (Patel et al, 2006). A study on behavioural implications on impoverishment in India, alcoholism, drug abuse and several ill habits related to poverty also contribute to mental health hazards (Prince, 2015).Lifetime risk of affective disorders, panic disorders, generalized anxiety disorder, specific phobia and substance use disorders is found to be highest among illiterate and unemployed persons (Deswal et al, 2012). Suicidal behavior was found to have relation with female gender, working condition, independent decision making, premarital sex, physical abuse and sexual abuse (Pillai et al, 2009). Ongoing stress and chronic pain heightened the risk of suicide. Living alone and a break in a steady relationship within the past year were also significantly associated with suicide (Manoranjitham et al, 2010). Work environment, school environment and family environment plays important role in pathogenesis of mental disorders. Females are more predisposed to mental disorders due to rapid social change, gender discrimination, social exclusion, gender disadvantage like marrying at young age, concern about the husband's substance misuse habits, and domestic violence (Patel et al, 2003). Divorced and widowed women are at slightly elevated risk of mental disorders (Patel et al, 2006). In India domestic violence is a big problem. A survey done in Maharashtra reported that 23 percent of women had been beaten in the last six months and of these 12 percent had explicitly been threatened to be burned (Jain et al, 2004). Poorer women are more likely to suffer from adverse life events, to live in crowded or stressful conditions, to have fewer occupational opportunities and to have chronic illnesses; all of these are recognized risk factors for common mental disorders (Kermode et al, 2007).

Stigma related to mental disorders, lack of awareness in common people, delayed treatment seeking behavior, lack of low cost diagnostic test and lack of easily available treatment are the main hurdles in combating the problem of mental health in India. In addition factors pertaining to traditional medicine and beliefs in supernatural powers in community delays diagnosis and treatment. India had focused its attention mainly to maternal and child health and communicable diseases (VenkatashivaReddy et al, 2013).

Recovery oriented Rehabilitation in Mental Health:-

Dutton et al outline the following as assumptions of the rehabilitation frame of reference: Compensatory strategies and techniques can assist individuals to increase their independence even when symptoms or illness persist. A person's level of motivation impacts on the extent to which an individual regains independence (motivation is a key element that service providers can influence). A person's environment impacts on their motivation to perform tasks (the environment can have either an enabling or disabling impact on an individual's motivation). Rehabilitation involves a learning process. Cognitive ability impacts on rehabilitation. Rehabilitation is an active process and requires effort. Rehabilitation needs to consider the holistic needs of the individual. Establishing a consumer-centred therapeutic relationship and having rapport impacts significantly on the rehabilitation process.

There are certain precepts that explain the recovery paradigm in rehabilitation of the mentally ill persons leading through capacity building frame work. They are;

Best practice rehabilitation is recovery-oriented. Recovery is the potential and actualisation of person's individual journey. Rehabilitation is the process and tools that practitioners utilise and provide to people to assist in their recovery journey. Rehabilitation should be available in all settings and begin as soon as possible. Rehabilitation practices should always encompass purposeful evidence-based best practice interventions. Rehabilitation techniques provide a range of tools that can be used to assist an individual to gain or regain their independence and strive towards their recovery. Rehabilitation occurs on a continuum. All workers need to understand rehabilitation but not everyone needs to be an expert in providing all interventions. Rehabilitation enables people to connect and become part of their community and be satisfied and successful in the living, working, learning and social environments of their choice. People with lived experience of mental illness and their carers should be key collaborators in the development, implementation, evaluation and modification of individual and group rehabilitation programs. The process of establishing a positive therapeutic relationship is a part of the rehabilitation continuum. It takes effort and time. Rehabilitation requires effort and engagement. Although it may not 'just happen' it rewards both consumers and practitioners. Rehabilitation will not necessarily lead to consecutive gains for consumers. Setbacks and overcoming setbacks are part of the rehabilitation process. Rehabilitation opportunities should be offered time and time again. Rehabilitation services that are shaped by goals of promoting hope, healing and empowerment ensure mental health services foster an underlying attitude that recovery is possible, offer opportunities for consumers to maximise their own experience of recovery, and create a service environment that is flexible, responsive and accessible. Rehabilitation is cost effective and reduces requirements for acute interventions Anthony and Farkas are very clear when they state: 'Psychiatric rehabilitation promotes recovery, full community integration, and improved quality of life for persons who have been diagnosed with any mental health condition that significantly impairs their ability to lead meaningful lives. Psychiatric rehabilitation services are collaborative, person directed and individualised'.

Community involvement in the rehabilitation process:-

Community involvement, engagement, empowerment, ownership and self-determination are widely acknowledged as key principles that underlie community development approaches to the advancement of mental health and wellbeing. In order to provide integrated services and opportunities for people to participate fully in the community, government and community agencies must work together regardless of traditional organisational boundaries. Partnerships lead to better integrated services. A community development approach to rehabilitation for mental health includes a move from an isolated treatment approach to one of collaboration, including a commitment from local community organisations to support rehabilitation initiatives.

Building the capacity of the workforce:-

At least two different levels of the workforce may be envisaged as necessary: 1) dedicated mental health promotion specialists who facilitate and support the development of policy and practice across a range of settings; 2) the wider workforce drawn from across different sectors such as health, education, employment, community and non-governmental organizations

Building the capacity of the workforce in developing and implementing mental health promotion programmes is fundamental to mainstreaming and sustaining action in this area. Workforce education and training range from awareness raising and training about the promotion of mental health for the wider workforce, to skills development needed to support and implement specific initiatives, through to dedicated mental health promotion specialists who facilitate and support the development and implementation of policy and practice across a range of settings.

Continuing professional development and training is required to enhance the quality of practice and update the skill set required to work within a changing context.

Capacity building of the consumers:-
The consumer empowerment projects include personal skill building exercises and reorienting health service needs as per the requirement of the consumers. Developing personal skills involves enabling personal and social development through providing information, education and enhancing life skills. Improving people's knowledge and understanding of positive mental health as an integral part of overall health forms an important part of this action area, highlighting the need for improved mental health literacy. Developing personal skills such as self-awareness, improved self-esteem, sense of control, self-efficacy, relationship and communication skills, problem-solving and coping skills have all been shown to improve mental health and to facilitate people to exercise more control over their life and their environments. Practice skills in implementing competence enhancement programmes are therefore required. • Reorienting health services requires that mental health services embrace promotion and prevention activities as well as treatment and rehabilitation services. This calls for a heath care system which contributes to the pursuit of mental health and wellbeing as well as the treatment of illness. In terms of mental health, this emphasises the important role of, for example, primary care and mental health services in promoting mental health across different population groups such as children, young mothers, people with chronic health problems, and mental health service users, their carers and families.

The above given information would be adequate to set the study focused on capacity building of the consumers in the individually driven family based and community oriented mental health rehabilitation model researched over here.

Methodology:-

The objective of the study is to find out the capacity building exercises done among the consumers in the rehabilitation centre. Qualitative research design with case study methodology is followed. The activities in each centre are considered as single case and four cases are chosen for this paper. Brief content analysis is done to explore the function.

Case study 1:-
Mr. Jose got inspiration from Mother Theresa to work for the poor. As he was staying in a hut on the Kerala-Tamilnadu border he observed truck drivers leaving mentally ill at Kerala border. On enquiry he found that as there was heavy rain in Kerala mentally ill were sent by their families to Kerala to get exposed to rain and get healed. There were some instances of such healing reported. Jose sheltered such destitute mentally ill persons and for the past 20 years he and his family take care of nearly 50 such persons. Being a layman in mental health profession he got support from the professionals of National Institute (NIMHANS) Bangalore. He adopted a capacity building model of family empowerment. The mentally ill persons are considered as family members and addressed 'MAKKAL', meaning to say children. The attitudinal difference towards the individuals made a paradigm shift in the approach of care giving. The love and care given to the mentally ill gave them great acceptance and rejuvenated their life potentials. The recovery was fast and nearly 2500 persons were sent back home healed through this capacity building model.

He also focused in awareness generation to remove the stigma in the community towards mental illness. He conducted classes in schools and colleges and got the service of the community to care the mentally ill. It generated pro-mental health attitude among the public. Family members of the mentally ill were given psychosocial support and trained them how to maintain drug compliance and to care the ill family member with dignity and love. It had reduced incidence of relapse and recovery rate shoot up.

Case study 2:-
A road accident and consequence medical care inspired Mr. Satheesh to undertake the care of the mentally ill. Today he and his family cares more than hundred destitute mentally ill. Mr. Satheesh being a layman in mental health profession had incorporated the capacity building of the inmates of the centre towards a friendly human approach. According to him, the poor should not be treated poorly rather richly. He tries to satisfy their small needs like food of their preference. It creates a favourable environment among the inmates. The symptoms of mental illness have done considerably. The number of people got cured in the past 18 years come around 1700 and were sent back home.

He says, the needs of the mentally ill are very simple but unique. If you could meet them it helps the client to co-operate with medication. Ultimately love and care is the best method to build the capacity in the clients. There are less incidents of patient violence reported in the centre.

Case study 3:-
From the background of pharmacist it was easy for Mr. Mathew to comprehend the dynamics of the care of the mentally ill persons. However it was hard for him to set foot in the rehabilitation process as it was a new field. Sooner he got the support of his family and the community. There are 150 male patients in the centre. Each individual is important for him and care him as his own family member. He calls them with a pet name which makes them closer to him. The capacity building strategy he followed is nothing but the personal care given to each and engaging each in one or other duties based on their skills and abilities. The house maintenance and works in the field is undertaken by the inmates. It keeps them engaged and less time to brood over their petty issues. The team of caregivers including the professional social worker had adopted the friendly behaviour with the inmates and created a family environment. Compared to the government hospital cum rehabilitation centre in the same city, this centre has less relapse incidence reported and better recovery.

Case study 4:-
Mr. Tony has a centre catering to 260 mentally ill persons. His life story is different. In order to feel the life of the wandering mentally ill he dressed himself like a mentally ill with shabby clothes, ate what they ate and slept on shop's corridors and experienced their life nearly six months to one year. The capacity building strategy he adopted has much to do with his personal experience. He sensed the needs of each individual and engaged them in different activities as per their capacity and illness behaviour. There are people work in the farm, help in housekeeping and others engaged in food preparation and serving.

Peer service is another strategy adopted. Those inmates who are less symptomatic mutually help in most of the self help activities including bathing and wash. The shaving and laundry are managed by able bodied inmates. Irrespective of inadequate living space the inmates are good harmony and less incidence of violence reported.

Analysis of the cases:-
All the four cases resembles the remaining 90 or more such centres in the state of Kerala. There are following capacity building strategies adopted in these care and rehabilitation centres.
1. Family based approach in which the inmates are considered as family members
2. Personal care and love creating a sense of self esteem and acceptance
3. Client interest is duly considered and petty wishes are satisfied through adequate attention
4. Engaging the clients in those activities suitable to each one's ability and capacity
5. Promote peer service among the clients and mutual support system creates better interaction and promotes recovery.

Conclusion:-
Irrespective of the inadequate professional background these layperson run rehab centres are turning out success in faster recovery, relapse prevention and more human care. The strategical approach for environmental manipulation catering to the needs of the clients and giving them a family feeling is major contributory factor in the capacity building. The mentally ill feel that they are included in the family and the community. Social inclusion is made practical through the participatory approach and mental health information dissemination at grass root level. Hence it is a model that could be widely replicated internationally taking care the cultural nuances.

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