Mental retardation – Role of parents

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**Introduction**

Karnataka Parents’ Association for Mentally Retarded Citizens [KPAMRC] is 26 years old now. The initiative to start this organization was many fold. The founder parents believed that the strength of the organization lies in several parents coming together for interacting, exchanging views and putting up a common front for achieving the desired goal, namely rehabilitation of their wards and enabling them to join the mainstream of life, like all others. The ways and means were many. The parents jointly made earnest efforts to move forward in as many ways as possible for achieving this goal.

The main focus of the parent is his ward, a special person who is also part of the community. Therefore, the Association took the first and probably the most important step to sensitize the people, the community and the society at large about mental retardation and other developmental disabilities.

Awareness campaigns, conferences, seminars and workshops, group and individual counseling and interpersonal communication were the tools which were effectively deployed to achieve this objective. Today, with certain amount of confidence one could say that this objective is achieved more in cities and urban areas. Efforts continue to spread it to the rural community and sensitize them about this major issue.

Interaction among the parents was encouraged to dispel the myth of destiny, karma, and the possibility of cure for this condition by medicine.

**Manpower Development:**

At the time the Association was formed there was hardly an institution giving training to special persons. The Rehabilitation Council was to come into existence much later. Training facility for the teacher was non-existent. The Association took upon itself to design the Teacher Training Programme, train teachers to be part of the special schools. NIMHANS was the first to come forward with its entire faculty to draw up the curriculum. Fine tuning was done later in consultation with experts of the Karnataka Government which readily recognized the six months certificate course which was formulated by the experts. Thus began a journey of manpower development in the year 1979. This was a pioneering effort on the part of the parents to find a way to facilitate the education of their special children. The Six month course was open and the focus of the training was skills. Over the years this certificate course became a one-year full fledged diploma course and now two year diploma course with the recognition of the Rehabilitation Council. Over the years two more courses, one in Autism and the other in Specific Learning Disabilities and Integrated Education were added with appropriate recognition by the National Council for Teacher Education. These two courses are one year duration and have the status of a diploma. The Association encourages parents to take these courses and today host of the parents are not only taking care of their wards at home but also working in special schools supporting the community at large. The Association is justifiably proud that over 1000 special educators are working in various schools in different parts of the state and even outside to help, develop the potential of the special person fully and become part of the mainstream.

Eligibility: Qualified teachers from regular schools, graduates / post graduates with teaching, degree qualified teachers in special education and currently employed as a teacher or parents of children with learning disabilities.

Focus of training; To provide trainees with the understanding of Specific Learning Disabilities as a major problem; to equip them with the knowledge and skills to help students teachers, parents, and administrators to cope with the problem and to enable trainees to implement the strategies involved in the process of Integrated Education of those with specific learning disabilities.

Skills expected;: They should be currently employed as a teacher or be a parent of a child with Learning Disabilities. To have basic knowledge of the condition of a persons with these disability.

Suitability of the trained persons to different settings: The trained persons can fit in both to the home environment and to the school environment. Parents who undertake this course will be able to assist and help their wards in the areas of disabilities of learning and also take care of persons with this disability in the neighbourhood. Trained teachers work in schools, both general and special to ensure that students with L.D. are trained adequately to join the mainstream which ultimately will be the objective of inclusive education

Trainers

The Association has also devised a four month programme exclusively for parents in Autism.

**Details for One year Diploma Course**

Eligibility for joining the course; Graduates / qualified teachers from special school / in special education or parents of children with autism

Focus of training: To provide trainees with the understanding of autism as a major problem that has recently been recognized as such. To equip them with the knowledge and skills to help students, teachers, parents and administrators of special / regular schools to cope with the problem. To enable trainees to implement the strategies involved in the process, in order that these children could be included into the mainstream of special / regular education.

Skills expected; should be teachers in special schools or have undergone special education course. Parents of children with autism are also eligible to take this course.

Suitability of the trained persons to in settings: Persons trained in this course can work in special schools meant for persons with autism spectrum disorder and multiple disabilities where autism is one of the conditions.

Trainers

Number of parents have taken this programme.

**4 MONTHS PARENTS CERTIFICATE COURSE**

KPAMRC organizes a 4 month certificate course for parents.

Eligibility: Any parent whose child is diagnosed with autism and who is willing to put in 4 hours of practical work with two children in an assigned institution and attend all theory classes once a week. The parents will be evaluated based on the set criteria.

Focus: To empower the parents with adequate knowledge about the disorder, its characteristics and symptoms. Also, to provide the parents with enough information on the management of the child’s everyday problems. The parents will be equipped to conduct an informal assessment of their children to understand the child’s difficulties and strengths. This will enable them to plan and carry out an appropriate educational program.

Skills: As mentioned above, parents will be equipped to evaluate their child’s performance in all areas of development, viz., language and communication, motor, cognition, play and social skills, self care and behaviour management. Based on this evaluation, they are then taught to plan an educational program that will be implemented consistently. This will reduce the burden on the parent in terms of understanding what to do so that the progress of the child is unhampered. Parents also learn about positive behaviour management which is very essential as persons with autism can exhibit very challenging behaviours. Suitability of trained persons: Parents training course equips the parents to handle their own children only but does not equip them to work as special educators in schools. Trainers: Same as the regular course

**Group Insurance:**

Another initiative taken by the Association as early as 1980 was to sign a memorandum of understanding with Life Insurance Corporation of India to develop Group Insurance Trusteeship Scheme [LITs] for the parents of the Association. This scheme was available at two levels. At the first level parents were to make a one time payment towards the scheme. The interest on this amount was paid towards the premium of the scheme and passing away of the parent, the amount insured, i.e. Rs. 20,000/- was given to the Association. The Association acting as Trust and guardians of the special persons, gives a monthly maintenance allowance of Rs. 200/- for the maintenance of the child. Parents were entitled to become members of this scheme till they attain the age of 60. At level two the amount was reduced to Rs. 500/- per parent and proportionately the maintenance was also reduced to Rs. 100/-.

The Karnataka Government showed interest in this scheme and signed an MoU with KPAMRC to jointly put this scheme into operation. The Karnataka Government paid the initial amount for insurance to the LIC and the other formalities was taken care of by KPAMRC.

A major problem faced by the Association today is to fulfill its commitment to pay the maintenance allowance. While rate of interest on deposit coming down drastically, paying Rs. 200/- and Rs. 100/- monthly has become a problem. KPAMRC is fulfilling its commitment by diverting money from its own resources. Most probably a re-look about the scheme is warranted at this stage.

**Parent Self-help group**

Another area of interest is the parent self-help group initiated by the members of the Association to help out parents of persons with mental retardation and other developmental disabilities, in the neighbourhood. To begin with a parent member identifies a place where parents can assemble interact, exchange their experiences and views and deliberate on an action plan to find a solution to the problems of their wards. The purpose of the meeting is explained and volunteers among them invitee parents to be available on each day during specified time. At that time parents can leave their wards in the identified place where the KPAMRC member parent organizes training in different vocations of interest to special persons over a period of time. Efforts are also made to market the products produced by these special persons and offer an honorarium.

Periodically, the self-help group arranges a picnic, excursions and visit along with the wards. Occasionally, experts and parents of the other self-help groups are invited for interactive sessions. This effort has helped the parents of these groups to come out of despondency, regain mental strength to move forward. This has also helped special persons to learn and earn depending on their ability.

AKSHARA Vocational centre – an initiative of one of the parents of our Association, Mrs. Jaivanthi Hiriyur, was started on 19-10-1992 at Malleswaram, Bangalore. This centre is self-help group activity led by Mrs. Hiriyur to help and assist persons with mental retardation and other developmental disabilities of neighbourhood. This centre admits persons aged above 16 years after properly assessing the abilities of special person. Depending on their ability training in vocational skills are imparted be it drawing, painting, and stitching, envelope making, and mats etc., along with some academic skills and special occasions the centre offers incentives to its wards depending upon the products sold. However, everyone in the centre irrespective of his ability to produce goods is given a minimum incentive to encourage them and ensure non-discrimination.

Custom design bhajans, excursion, sports and games are other co-curricular activities which keeps the special youngster motivated and members of the self-help group a recharged lot.

IF possible could you describe one such group And its activities

**Caregiver Programme:**

KPAMRC, was most probably the first Association to think in terms of organizing a training programme to train persons who could act as caregivers and work with families in their houses and relieve the parents to have a respite.

The first programme was organized jointly with Spastics Society of Karnataka.

Eligibility; Adults with working knowledge of the regional language in reading writing and conversation.

Focus of training; Familiarization of disabilities, namely: mental retardation, cerebral palsy, autism, polio militias, basic principles of managing persons with these disabilities.

Skills expected; Familiarity in handling and managing children in home and institutional environment.

Suitability of the trained persons to different settings: Persons trained in this course are to assist the families having persons with intellectual disabilities as caregivers, depending on the requirement of the families, they could help the family by taking care of these special persons for a few hours every day or for a few days or on a regular basis. These caregivers were also available to the institutions to provide the required support in managing the special persons.

Trainers : Professionals working in the field on intellectual disability

Today, this programme after refinement is being implemented by the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and Rehabilitation Council of India. The programme is of six months duration and any NGO registered with the National Trust is eligible to organize this programme. KPAMRC is one of the pioneers in the country to have organized this National Trust programme which has helped to create a core of caregivers.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities under the Ministry of Social Justice and Empowerment launched in a big way to develop a band of caregivers to help and assist parents at their homes and work in institutions meant for persons with mental retardation and other developmental disabilities. Master trainers who would in turn give training to grassroots level. Caregivers were initially given training at the premier National Institute for Mentally Handicapped [NIMH]. These Master Trainers coming from all parts of the country have trained the grassroots-level caregivers and till the end of March 2004 nearly 2000 trained caregivers were working in various parts of the country. Among them over 50% were home based caregivers. This programme was temporarily discontinued from the middle of 2004 as it was felt that caregivers are also to be given registration under the Rehabilitation Council of India. Now the National Trust has reintroduced caregivers programme with the desired modification.

**PARIVAAR -- National Federation of Parents’ Association**

Most probably one of the initiatives of the Association which made a great impact at the National level was the initiative taken by the KPAMRC at the World Congress organized by the ILSMH in 1994 in New Delhi. There were representatives from various parts of the country attending the Congress and on the initiative of KPAMRC they discussed the formation of a National Federation of Parents Associations. This idea was accepted in its totality and the President of KPAMRC was elected to head an adhoc committee with a mandate to work out the modalities and the constitution to form a National Federation called PARIVAAR. This committee held a few meetings and finalized the constitution with a provision to have two levels of membership, the first one full fledged members eligibility being only parents association working in the field of mental retardation, autism, cerebral palsy and multiple disabilities, the other was affiliate membership to Associations of professionals and NGO working in these four disability areas. The Association was registered in the year 1996 and during the last 10 years it has grown from strength to strength.

The Federation which had initially only 22 parents’ associations as its members at the time of formation, today has nearly 150 members. It has become a strong force at the national level being in the forefront of advocacy for persons with mental retardation, autism, cerebral palsy and multiple disabilities. It has also made an impact at the International level and is a member of Inclusion International. The Federation and Inclusion International have signed a MoU to mobilize and strengthen parents movement in India. This activity is going on for the last six years and the movement has spread even to rural areas in North-East and North West.

Parivaar is actively involved in providing different skills to its members to manage and implement various rehabilitation programmes meant for their wards effectively. As a part of this, Parivaar has organized workshops to impart managerial skill and skills on effective communication. Workshops have also been conducted to build leadership quality among its members. Parivaar is constantly interacting with Government of India and other national, international bodies working for the disability sector to develop an effective network.

The Honorary Secretary of KPAMRC is heading the organization as President of Parivaar and overseeing these activities.

**Group Home:**

All these 26 years KPAMRC firmly believed in the philosophy of just being a catalyst in promoting various rehabilitation activities for its wards through other interested NGOs. At times it acted as a trouble shooter with the completion of the Silver Jubilee. The Association decided to undertake projects with a role model for replication by parents association elsewhere. The foremost among them was to develop a group home complex where facilities for long-term residential care and rehabilitation will be available to persons with mental retardation and other developmental disabilities. Side by side it also agreed to provide facilities in the complex for senior parent couples to stay there. Undoubtedly, facilities are available for long-term residential care of special persons all over the country but these places have no arrangements to provide the much needed love and affection to these special persons which can be given only by parents. That is the reason why in the Group Home complex it was decided to make arrangements for senior parent couple to stay there. These parents who oversee the activities of the complex will also provide the much needed love and care to the residents. The complex will also have facilities for vocational training and sheltered workshop. A day-care centre will function which will be utilized both by the residents and the neighourhood.

The complex has been planned about 25 kms away from Bangalore in a rural setting. Hopefully this complex will become the forerunner for the establishment of many more such complexes all over the country. The establishment of this complex in a way answers the haunting question of a parent ‘After us what?’ by providing a home away from home.

**Books and Publications:**

KPAMRC always believed that interaction among the members and other like minded people was a vital input such growth it started with a quarterly newsletter just after a few years of its formation. The newsletter contains information about policies and programmes initiated by the Government, various activities undertaken by NGOs working in the field and of course major activities of the Association. Even today the newsletter continues to be the major link among the members of KPAMRC knowing the importance of knowledge dissemination among its members and other organizations. The Association also began publishing books and manuals on issues connected with mental retardation and other developmental disabilities, management of special persons, guidance to parents in managing their wards and training manuals to the teacher trainees. The first publication came out in early 90’s and so far the Association has published 12 publication on different topics.

In addition special issues and souvenirs were brought out on major occasions like National Parents meet, national seminars and workshops.

**Professionals Support:**

KPAMRC has been getting spontaneous, unhindered support from professionals and experts. Thanks to its location in Bangalore. The Association from day one started interacting with professionals and experts of NIMHANS. The response has been overwhelming. Doctors in NIMHANS guided the Association in developing the curriculum for all the three diploma courses namely mental retardation, autism and specific learning disabilities and integrated education.

These experts and professionals were available to constantly review and update the curriculums. They and professionals working in other major institutions in Bangalore have been teaching these students of all the three diploma courses as guest faculty. The professionals are also on the Technical Advisory Board of KPAMRC to guide and steer professional activities of the Association. Parent counseling and guidance has been a continuing activity over the years. Parents and professionals have developed respect and regard for each other over the years with constant interaction with each other.

**Barriers**

It has generally been a smooth sail for KPAMRC despite facing road blocks now and then. All in all it has been a very positive growth.

It has been one of the aims of KPAMRC to work with other disability organizations for the common cause of welfare and rehabilitation of persons with disabilities. While working of and interacting with other NGOs there were in ego clashes. Discussions at length and appreciation of each others point of view has helped to resolve the issues.

Most important among the handicaps in the growth of the Association is the lack of involvement of younger parents. Efforts in this area have not yielded much result. Once in a way a parents shows interest but it is short lived. The Association fully appreciates, the commitment of the younger parents towards their families. It also understands that they being the bread earners of their responsibilities towards the family are very important.

The Association also appreciates that being young one has the attitude of concurring the world. Unfortunately, the efforts of the Association to dispel this myth has not proved successful. May be this issue is not confined only KPAMRC by the entire universe. It is here networking at a higher level to workout modalities and techniques to overcome this major hurdle is required.

Finance is another area which retards the growth of the Association. Occasionally, frustration creeps in. Interaction amongst parents and like minded people along with the reworking of the programme gives way once again to buoyancy and optimism.

**Future Plans:**

The Association has drawn up ambitious plans for further growth. Among them the enrolment of the more members. It has planned to increase the membership by at least 10 fold during the next five years. Supporting parents to start parent associations both at district and taluk level is another activity. Networking of association working for the same disability and networking with other disabilities at three levels taluk, district and state is also an important point in the plan of action.

One of the major future plans of KPAMRC is to have its own facility which will house the teacher training programme, library and a big auditorium, counseling and guidance centre, day care centre, vocational training and sheltered workshop, respite care, and facilities for research all under one roof in Bangalore.