**Involvement of Family in the Comprehensive Rehabilitation of A Child With Visual Impairment**

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" Parents may find comfort, I say in learning that their children are not useless, that their lives, limited as they are, are of great potential value to the human race. We learn as much from illness as from health, from handicaps from advantage- and indeed perhaps more." Pearl S. Buck.

INVERTED PYRAMIDS

No one plans to have a child with disabilities. The birth of a child with a disability is an unanticipated event. No family- regardless of race, ethinicity or socio economic status- is immune to childhood disability, yet almost all are poorly prepared to cope with its occurence. (Selgiman & Darling)

The family is the first social unit of the child and its first center of learning. A professional may initiate, intervene or plan a rehabilitation programme but the child remains in the fold of its family. It is thus imperative that the family is involved in the comprehensive rehabilitation right from day one\_\_

The parents, grandparents, siblings and the typically extended family are a vast pool of talent that lies underutilised at present. The rehabilitation scenario largely in the developing world is of a"top-down" model or that of an "inverted pyramid" with medical and rehabilitation professionals "prescribing" the treatments and actually"giving" it to the person with a disability without involving the family. This rehabilitation model is top heavy with a huge team at the top and very few or no workers at the grass-root level. The person with the disability is surrounded by a tight chain of rehabilitation workers with parents generally neglected. This has resulted in:

- isolation of such a child from her family
- a withdrawal of parents from the child and her development
- ignorance and apathy of the potentials of this child
- mystification and fear about the disability and its impact
- polarisation of the child with the disability from the "normal" family.
- Institutionalisation of services.

A state of limbo persists after the person with the disability has "completed" her rehabilitation training. The family is unable to readjust to this person and understand her needs. The rehabilitation agency "disappears" after its role is over leaving the person with the disability to flounder in an atmosphere which has not been cultivated or sensitized. Rehabilitation programmes thus do not become self-sustaining nor do they get internalised in the community. Rehabilitation professionals are "outsiders", however close, sensitive and caring they may be, they have a limited role to play with a particular child. Their job is to move on to the "next" child in need.

BRIDGES INTO THE FAMILY

All over the world, awareness has been generated that there have to be bridges into the family, community and the professionals. If one has to make use of such a priceless and vast resource the family as the primary care giver of the child has to be roped in.

Untill recently, professionals in the rehabilitation field took a primarily client centered approach with the focus on the individual's handicap. There is now a realization among specialists that these individuals cannot be viewed as isolated entities. They need to be seen within their familial and societal contexts because of the reciprocal and interdependent relationships between such individuals and their families, and the influence that the family exerts on their overall development. Since the family can play a vital role in supporting such a member, its direct involvement in the rehabilitation process as an active partner in the multidisciplinary team is increasingly considered necessary. Moreover, it has been accepted that the overall goals of rehabilitation are the attainment of integration and equalization of opportunities by them in every facet of daily life, including a share in the normal social life of the family and the community.

The interaction between professionals and parents is often marked by confusion, dissatisfaction, disappointment and anger. All research information, however, proves that these are the initial stages which soon are transformed into mutual respect and give and take.

Effective partnership between professionals and families would depend upon

- Patience, sympathy and openness on the part of the helpers to understand families perspective
- Doing away with the concept of withholding of information concerning a disabled person
- Discretion in discussion with family
- Involvement of parents in planning and decision making

For the parents to be true partners in rehabilitation,it is essential that the professionals accept that:

- The parents have a right to be involved in the planning, as the child is their ultimate responsibility.
- That the home is the large canvas of the child's life as she spends the major part of her life there.
- That parents are aware of the problems of the child but not able to gauge the impact of disability.
- Parents have a major contribution to make in the life of the child.
- Professional efforts would not yield full results without family involvement.
- Parents have a right to know the various range of services and options available to the child and the right to choose the most practical one.
For the family to be successful in the rehabilitation process of the disabled person, it is essential that:

- There is demystification about disability. The family does not get confused and bogged down by labels and jargons but are told about the impact of the disability and the abilities of the child.
- The family as a whole decides to put itsbest foot forward to learn, to experiment, with ideas and understand, accept and love the family member with a disability.
- The disability is accepted by one and all and it is acknowledged.
- The family is open to ideas from the professionals.
- That the family is made aware of rehabilitation methods and avenues open to the child.
- Thefamily members are present in decision-making process.
- The family members faithfully adhere to their part in the rehabilitation of the child.

The Family as Partners in Rehabilitation of a child with Visual Impairement

The family members, relatives, friends and the community at large must be involved in the rehabilitation planning of the child The family is the first and main focal point and if it is roped in, counselled, trained and convinced, it can spread the message and convince other members of the community. Any technical and professional training by the professionals can be reinforced by family and this change can be sustained. The family can inturn motivate and influence the community to accept all persons with visual impairment. This change would be inbuilt, self sustaining and would not disintegrate after the professionals leave the scene. Various benefits of specialized training by professionals would be absorbed by the family. They would accept the person with disability and treat her with respect. This change would slowly percolate and become a way of life in the community.

The model below gives an illustration of how professionals and parents are two sides of one coins and both are interdependent for the effective integration of the child into normal life. For the parents to be ultimately responsible, it is essential that they are trained and sensitized. Figure I gives the parental training model and Figure II gives the interaction of both.

Other practical examples of family involvement are grandparents providing respite care to the parents of the person with visual handicap, sharing chores to provide relief to the parents; siblings providing help in education, participation in play activities and participation in peer group activities and relatives involving the visually impaired person in the family functions and economic activities.

The parents who are aware and trained can be effective in training other parents having disabled children. They can form parents groups, self-help groups for their child. The parents and the family members can gain knowledge and skill and become full-fledged teachers or back-up or support teachers for their children.

CONCLUSION

To acheive comprehensive rehabilitation and sustain it once the professionals and NGO's leave the scene, it is imperative to wake these families from stupor of their conventional believes, train them to deal with this phenomena, guide them to search out appropriate education and training, from the various facilities available for their child so that she can become self-reliant, contributing member of the family and consequently the community. With the limited human and other resources available with the professionals working in this field, if the families can take over from them at a particular stage, it would leave professionals more time and energies to apply the same elsewhere with the satisfaction and knowledge that their earlier work will continue with the help of the families and the communities.