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ABSTRACT

This report describes Hong Kong's first parent resource center for parents of children with handicaps, which opened in August 1990. The need by parents for emotional, educational, material, and other support and services is documented. Parents of special children are seen as a resource for each other and as advocates for their children. The report describes establishment of the resource center and its services, which include a hotline, a resource library, a toy library, professional consultation, educational talks and skill training sessions, social and recreational functions, and peer counseling by parents. Future directions include outreach programs and development of a second center. Statistics on membership, service utilization, and programming are attached. (12 references) (DB)

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"CROSSING BOUNDARIES ; ENSURING QUALITY"

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A Small But Sure Step: Hong Kong's First Parents Resource Centre

Introduction

On 1st August 1990, Hong Kong's first Resource Centre dedicated for the needs of parents with special children began to operate. Although the Centre occupied only some 120 sq. m. on the ground floor of a public housing estate situated in one of the most densely populated cities of the world, it has lighted up the hearts of hundreds and thousands of parents with special children. At last they can have a place where they can share, learn, grow and work together amidst the misfortune of having children with handicaps.

Parents of special children need support

Up to the early 1980's, rehabilitation services in Hong Kong catering for the needs of some 200,000 people with handicaps were very much patient-focused. This means that the services were centred around the handicapped person's needs, while their significant others were treated as providers of support for the handicapped instead of people having their own needs.

With cumulative experience in the field, and growing access to overseas references, it became clear to the local rehabilitation personnel that some adjustments in this attitude is in order. Fortier and Wanlass (1984) reviewed 20 years' research literature on family reaction to the diagnosis of a handicapped child. They concluded that subsequent to the diagnoses, these families often had to face a series of crises (impact, denial, grief, focusing outward and closure) affecting their behaviour, affect, sensation, cognitions and interpersonal relations. Kew (1975), Vadasy, Fewell, Meyer and Schell (1984) stated that these crises not only tied down the parents of the handicapped children but also disturbed the lives of their siblings. Lau (1989), who has been serving in a Child Assessment Centre in Hong Kong for the past 13 year, also concluded that "There is reasonably firm evidence that all families with a handicapped child are subject to increased stress and strain and many families we came across were in particular need of social and emotional support."

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To pin down the specific needs of these parents, efforts were made to delineate the nature and sources of stress faced by these parents. The Parenting Stress Index developed by Abidin (1983) grouped the stress factors into three domains: Child Characteristics, Parent Characteristics, and Life Stress Events. Examples of Child Characteristics include demandingness, distractability, mood instability, while examples of Parent Characteristics include depression, restrictions of role, social isolation, tension with spouse etc. Subsequent overseas and local studies using multiple comparison groups and involving fathers in the studies (Noh, Dumas, Wolf and Fisman, 1989; Chee, 1991) supported the impression that the presence of an exceptional child makes the parenting role more difficult, and also pointed out that the fathers might be more vulnerable than the mothers in absorbing the shock of having a handicapped child.

Finally, current trends of deinstitutionalization, normalization and integration encouraging the parents to provide opportunities for their special children to interact with and learn from their normal counterparts, are, in a way, additional demands on the parents' energy. All these call forth efforts to shift the focus of support from the handicapped persons alone to their immediate family members. Currently, increasing considerations have been given to Cobb's model of social, instrumental, active and material supports (McCubbin, 1982), and strategies of counselling and helping these parents were further developed (Ratcliff, 1990).

Parents of Special Children as Resources

While concerns on parenting stress seem to portray the parents of special children as passive recipients of services and support, the fact remains that such parents have their active and positive parts to play. In terms of parental involvement in early education, Guralnick (1989), in a Symposium on Early Special Education held in Hong Kong, described two forces in what he called "the second generation of early intervention programmes". One force suggested a more equitable parent-professional relationship i.e. parents should be a contributing and integral member in the treatment team instead of a follower of the team's instructions. The second force suggested that parent-child interaction should shift from instruction-focused to relationship focused because research repeatedly demonstrated that a more natural parent-child relationship is often facilitative of, if not crucial to, substantial and long-standing training effectiveness. These forces imply that parents should and can help to promote the education and emotional life of their children, and they are actually assets in the helping process.

Besides benefitting their own children, parents' contributions can be extended to group and policy levels. Studies on the functions of self help groups (Chan, 1991) indicate that by virtue of their direct involvement with the handicapped persons, the parents are adepts in identifying service gaps and acting as advocates for filling in these gaps. This means that the parents have a very important role to play in terms of qualitative and quantitative advancement of services.

However, parents associations often have to face the problems of no regular meeting place, no one to look after their children when they attend meetings, no access to educational and recreational resources suitable for families of their nature, and limited access to new services developments, etc. It is thus obvious that something has to be done to help them overcome these problems before they can optimize their functioning.

Establishment of the Parents Resource Centre in Hong Kong

It is against this background that some of the rehabilitation personnel in Hong Kong began to engineer the establishment of a Centre for such parents to meet their needs in overcoming their unique problems of living, and to utilize their strengths for their children's benefits. In November, 1989, the Heep Hong Society for Handicapped Children, which has been serving pre-school handicapped children in Hong Kong for more than 25 years, decided to set up the first Parents Resource Centre in Hong Kong. The objectives of the Centre included providing facilities and resources for the parents in areas of rearing special children and betterment of family life; offering a meeting place for mutual sharing and support; and facilitating the parents in advocating for the rights of handicapped children.

The decision encountered very favourable response from the parents, professionals, and last but not the least, the government. Although the government was not yet able to allocate regular subvention to the Centre, the provision of a suitable and accessible site greatly facilitated the setting up of the Centre, which finally came into operation in August, 1990.

Services of the Centre

In line with the belief that parents can be takers and givers, services of the Parents Resource Centre have also be developed along these two dimensions. Services offered to the parents include

1. a hotline service which provides timely and update information on services available for handicapped persons and their families in Hong Kong.

2. a resource library where the parents can come and consult local and overseas literature concerning rehabilitation of handicapped children.
3. a toy library which loans out a variety of educational toys.
4. professional consultation on a group, and if necessary, case basis. Currently, a total of 15 professionals including Paediatricians, Psychologists, Therapists and Lawyers are volunteering their services to the Centre.
5. educational talks and skills training workshops to enhance the parents' knowledge and skills in handling their normal and handicapped children.
6. social and recreational functions like outings and interest classes to promote the quality of life of these families.

At the same time, the Centre has been very concerned about making good use of the parents as resources. Aside from the more conventional channels of using parents as manpower resources in mass programmes of the Centre, getting them involved as editors of the Centre Newsletter, or inviting them to be instructors in short-term interest groups, the Parents Resource Centre has been involving parents on higher levels of services : management and paraprofessional levels.

Basically, parental contribution to the Centre should be dated back to the planning stage of the Centre because parents constituted a substantial portion of the Organizing Committee of the Resource Centre. After the Centre was established, its Management Committee has been chaired and manned by the parents, while the staff and some volunteer professionals only served in the Committee for administrative and consultative purposes. Experience so far demonstrates that participation at the management level helps the parents feel equal with the staff and professionals, thus directly enhancing their confidence to contribute to the Centre and to their children.

Since early 1991, the Parents Resource Centre has invested further in developing parents as peer counsellors for other parents. The Parents Ambassador Scheme trained up 14 parent counsellors. Their first venture is the "Twilight -- Parents Mutual Help Project", which will start in late 1991. In this project, parents who have just learned of their child's handicap will be provided with the knowledge and information necessary to begin helping their children. The programme incorporates the crisis intervention model into some outreaching casework as well as centre-based educational talks. It will be manned by the Parent Ambassadors under the supervision and support of some professionals. It is hoped that this "early intervention programme" tailored for the parents taking the shocks of the diagnoses can be of substantial help for them.

Future Directions

Since the inception of the Centre, 0 families have enrolled as members and close to 6,000 people have used the Centre's facilities or participated in its activities. Around 1,000 visitors have also made a trip to see the Centre in person. More efforts in out-reaching work have also been achieved through the "Twilight Project", where potential members will be informed of the availability of the Centre through the Child Assessment Clinics.

As one celebrates the apparent success of the Centre at its first birthday, the very active and dynamic parents have been pressing for more in the years to come. Aside from qualitative and quantitative enrichment of Centre programmes, efforts have been made to promote the image of the Centre not through mere propaganda, but by reaching out to the community to provide voluntary services to other needy groups in the community. Examples are setting up a gateway club for adult mental retardates, provision of hair-dressing service for the residents in Elderly Homes, and participation in the Round Table Fund-Raising functions. It is hoped that through participation in such projects, the community can be better educated about the nature and function of the Centre, thus facilitating future advocacies for rehabilitative services.

Last but not the least, chances are very high that the government is going to demonstrate its support for the Centre by allocating another site in the New Territories so that another Parents Resource Centre can be set up. While this means more work for the parents and staff, this also means the past efforts have been recognized, and the rehabilitation services in Hong Kong is finally moving step by step onto a family-oriented approach.

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Heep Hong Society for Handicapped Children
Parents Resource Centre
Service Statistics (September 1990 - August 1991)

(I) Membership

Type of Member	No.	Remarks
Ordinary	506	For parents and family members of handicapped persons. Ordinary members have to renew membership annually.
Organizational	2	For registered parents' organizations.
Affiliated	54	For people who are interested in the services for handicapped persons.
Total	562	

(II) Utilization of Centre's Services

Nature of Service	No.
1) Frequency of visits by parents	5,667
2) Frequency of members using the resource library e.g. borrowing books, cassettes and video-cassette tapes	1,776
3) Frequency of members using the toy library, e.g. borrowing toys	1,477
4) Counselling and referral cases	56
5) Hotline service	221
6) Professional consultation service	
i) No. of sessions conducted	23
ii) No. of users	112
7) Booking of centre facilities for holding meetings	
i) No. of applications	41
ii) No. of users	855
8) Visits to the centre by other organizations (by agency)	112

(III) Programmes/Groups Organized

Nature of Programmes/Groups	Frequency	No. of participants
1) Parent Ambassador Scheme	11	147
2) Parent Support Group	8	80
3) Sibling Group	2	20
4) Editorial Group for Newsletter	17	186
5) Educational Talks	11	354
6) Parenting skills training	17	172
7) Toy exhibition	1	26
8) Social and recreational functions	15	106
9) Interest class	63	560
10) Orientation for new members	6	192
11) Opening Ceremony & Annual General Meeting of the Centre	2	400
12) Others (e.g. briefing of volunteers)	4	52
Total	157	3,438