PARENTS AS PARTNERS IN THE TRAINING OF THE INTELLECTUALLY DISABLED CHILD: THE CASE OF PENANG ISLAND, MALAYSIA

by

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(i) the sharing of information and skills.

(i i) the sharing of feelings and perceptions.

(i v) a shared process of decision-making.

(v) a recognition of respect for the individuality of families and of the child. Implicit in this, is the criterion of "openness" on the part of both parties, but more so on the part of the professionals/teachers.

IMPORTANCE OF PARTNERSHIP WITH PARENTS

Bronfenbrenner (1977) has stated that ecological principles are increasingly important in the framing of services to children. The development of individual children can only be understood in relation to the various environment in which they live and to the complex and continuous interaction which occur between them and the environment. Thus children's development and the environment are interdependent and for any effective intervention or training to take place, it needs to take into account the different nested levels of environment systems in which the child is a participant, namely parent-child interactions, the home, the extended family and the community.

O'Dell (1974) suggested that utilising parents to deal directly with the learning problems and skill deficits of their children may be seen as an area of preventive mental health. The reasons being firstly, parents have an important influence in the formative pre-school years and are often in the best position to prevent the development of problems. Secondly, the number of children in need of services and the shortage of

professionals mean that it is only parents who are available in sufficient numbers to help with the problems. Thirdly, there is a growing amount of evidence which suggests that individuals who wish to effect long-term behaviour change must work in the person's natural environment (Tharp and Wetzel, 1969). Over the last fifteen years, an increasing number of studies have demonstrated that parents could be taught the skills to modify or change the behaviour of their children (Heifitz, 1977).

Hobbs (1975) argues that in terms of intensity, frequency and duration of contact, parents have a very significant advantage over the professionals. Since the parents are more available than professionals, the training of parents can be seen as a way to bring about desired outcomes in the children or as Cunningham (1985) puts it, as a way of increasing the efficacy of parent-child interactions. Parents are also in an optimal position to increase the probability that solutions which have been worked out in the classroom or in the therapists' office will be transferred to the home and community (Fredericks *et. al.,* 1976). Parents can be taught to evaluate their children's motivations and these evaluations can serve both as a source of information for the therapists and teacher and as an extension of the therapist's and teacher's efforts (Altman and Mira, 1983). Parents can also learn to intervene in a systematic fashion and thus promote the generalisation of behaviour learned in the clinical training setting to the home (O'Dell, 1974). Furthermore, involving parents in the training of their intellectually disabled children may focus attention on problems that may otherwise be overlooked when therapeutic effort is invested mainly in treating the children with disability (Kravetz, Katz and Katz, 1990).

Studies by Zaman and Islam, 1988; Laski *et.al.*, 1988; Fukushi, 1988 and Howlin. 1989 have shown that if parents are involved in teaching their disabled children at home, skills acquisition would be achieved at a faster rate. This is only possible if parents know what and how to teach. Hence, the need for professionals/teachers to include parents in the training of such children.

Most societies assign to parents the role of socialisation agents of their children. Thus, training parents and modifying parents' attitudes so that they can fulfill their role more effectively and appropriately should be more harmonious with role expectations of parents (social norms) than would be transferring a major portion of the parental role to the professionals (Hobbs, 1975). Hence, for effective rehabilitation process of the intellectually disabled child to take place, the focus should not only be on the child but also on the parents.

In the Malaysian context, the rehabilitation/training of these children has been and still is the responsibility of the professionals.

Parents have the notion that the educational and training needs of the child are to be met by the professionals and that as parents, they are in no capacity to do so. Yet studies have shown that effective rehabilitation can only take place if parents are active partners in the whole process. This implies a two-way process whereby parents are given the opportunity to discuss and share with the teachers/professionals their own fears and anxieties as well as knowledge of their child's strengths and weaknesses and their problems in handling their child. This would reduce the anxiety and stresses of parents which indirectly affect their coping capacity and their caregiving roles.

In this respect, professionals should also work with parents, not only in the area of skills training but also on the social- psychological domain because the state of psychological well- being and mental health of the parents would influence the treatment of the intellectual disabled child. To this end, the rehabilitation of the intellectually disabled child should focus on 3 main components, namely the problem (that is the child's specific skills development need and accompanying teaching techniques), the social environment and the psychological make-up of the parent. Figure 1 denotes the framework for partnership with parents in the rehabilitation of the intellectually disabled child.

Based on this framework, a study was conducted on the feasibility of involving parents (or care givers) in the rehabilitation process of the intellectually disabled child.

OBJECTIVES OF THE STUDY

The objective of the study is to examine the feasibility of partnership with parents in the training of the intellectually disabled child, using 3 different interventive modes. The modes of training are:

i Mode A: where the model of training included weekly demonstration sessions on their child also known as role modelling sessions with verbal instructions, and weekly home visits as follow-up by the researcher. The demonstration sessions were centre-based to enable parents to interact and build a relationship among themselves and in the course of it to derive support from one another. Home visits

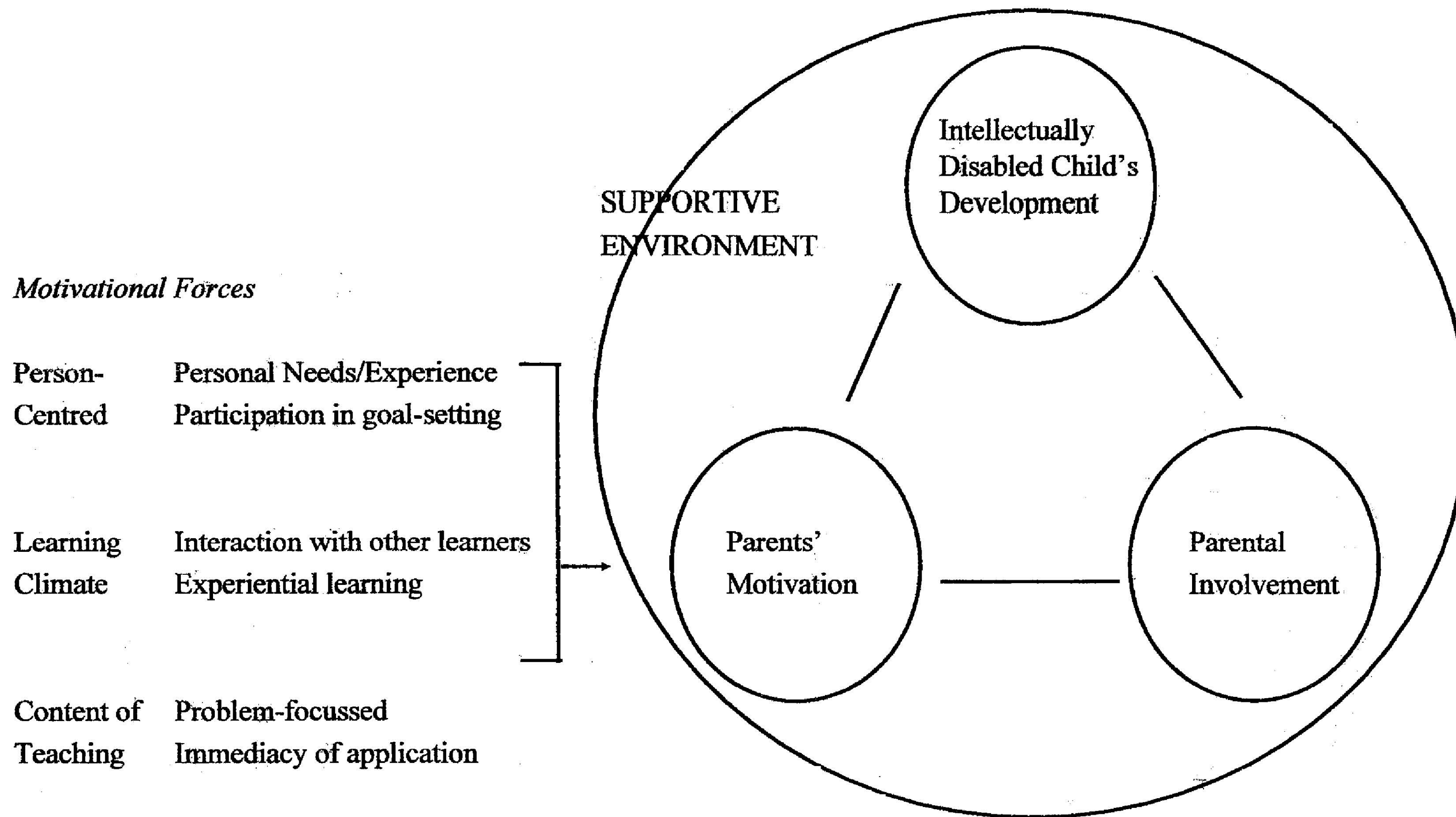

Figure 1: Parental Involvement Process

were carried out not only to ensure that parents were able to generalise the skills but also to understand the physical, social and psychological environment which surrounds the child. The physical environment would refer to resources available at the home which could be used for training and the actual space and set-up in the home.

The social and psychological environment would include family dynamics and its effects especially on the parent trainer. This aspect would focus on the "person" in the parent trainer. In short, this model of training did not only focus on skills training of the child but also on the psycho-social support needed by the parents in their parenting roles.

ii) Mode B: where the training model consisted of the weekly demonstrations/role modelling sessions with verbal instructions. These sessions were also centre-based and individual parent practised on his/her child the skills agreed upon.

iii) Mode C: whereby parents/caregivers were only subjected to the fortnightly workshop or lecture sessions. These sessions were conducted at a designated centre and each session lasted for 2 hours. Video tapes were also utilised as an instructional aid where necessary.

METHODOLOGY

The study was conducted as a follow-up of an exploration on the characteristics and situations of parents of the intellectually disabled children under study.

The sample for the study was taken from two centres for the intellectually disabled in Penang Island. Only those children who were intellectually disabled but not physically disabled were considered. A total of forty seven children with ages of 6 to 15 years form the sample.

This study was quasi experimental study involving 3 treatment groups and a control group. Parents were randomly selected into each of these groups. To ensure that there was no contact among the four groups, a specific day of training was allocated for each group of parents. Training lasted for 8 months. The Adaptive Behaviour Scale by the American Association on Mental Deficiency (AAMD) was modified and utilised to assess the children's performance before and after the research period.

Analysis of covariance using the pretest score as covariate and the posttest score as dependent variable was utilised to determine if there was any significant effects on the modes of training. Duncan's Test was used to test the significance of the training modes. Level of significance was set at 0.05.

Discussion of Findings

At the end of the study, the number of subjects in Group A,C and Control remained at 12 each while the subjects in Group B dropped to 11. This was because one of the children passed away after the second month of the research period. Thus the final results were reflective of forty seven children.

Table 1-a shows the pre and posttest scores of the children in independent functioning while **Table 1-b** shows the ANCOVA of the groups. **Table 1-c** shows the results of Duncan's Test.

Table 1 (a): Pre and Posttest Mean Scores of Groups A, B, C and Control Group

Variables	Highest Score Renge	Group A (N=12)		Group B (N=11)		Group C (N=12)		Control (N=	
		Pretest	Posttest	Pretest	Posttest	Pretest	Posttest	Pretest	Po
Eating	17	8.25	13.75	10.64	12.64	9.92	10.33	5.33	5
Toilet use	10	3.58	9.25	3.64	5.00	3.75	3.83	2.67	2
Cleanliness	24	7.75	10.67	7.91	8.64	9.33	9.33	6.25	6
Appearance	8	6.58	7.08	7.00	7.00	7.33	7.33	6.33	6
Care of clothing	4	0.58	3.00	1.27	1.55	1.33	1.75	0.50	0
Dressing & undressing	14	4.92	10.67	5.73	8.27	5.75	6.25	3.67	3
Travel	3	1.42	1.92	1.55	1.64	1.33	1.42	1.25	1.
Other independent functioning	8	1.92	2.17	1.82	2.09	1.83	1.83	1.08	1.
INDEPENDENT FUNCTIONING	88	35.00	58.50	39.55	46.36	40.75	42.00	27.53	27
Increase of		23.50		6.81		1.25		0.30	

Table 1 (b): ANCOVA for Overall Independent Functioning

Source	D.F.	Sum of Squares	Mean Square	F Value	F Probability
Model	4	1614.232	1903.558	184.69	0.0001
Error	42	432.875	10.301		
Corrected Total	46	8047.106			

$p < .05$

Table 1 (c): Duncan's Test for Overall Independent Functioning

Status	N	Posttest Means	Significance
Group A	12	58.50	B, C, Control
Group B	11	46.36	A, C, Control
Group C	12	42.00	A. B. Control
Control	12	27.833	A, B, C

Effects Of Training

The results showed that at the end of the research period, the posttest scores in independent functioning of all children had increased (**Refer Table 1-a**). The highest gain of 23.5 points was recorded by the children whose parents had mode A of training. This was followed by Group B children with a gain of 6.81 and Group C with a gain of 1.25. This change could be attributed to the fact that mothers who were previously ignorant of the whole learning and developmental process of children with intellectual disability were exposed to information and techniques of teaching and handling such children. Moreover, the interaction among mothers during the training period and the exchange of information indirectly had given mothers the motivation to teach their children. In other words, the psychological support derived from among themselves was also a contributing factor to their change in attitude regarding teaching their children at home. Another motivating factor could be the individualised manner in which the training of the mothers was conducted and the availability and willingness of the researcher to listen to the many problems of being a parent of an intellectually disabled child and trying to work out practical solutions to their problems together with them.

Out of the variables in independent functioning, the variables that recorded the highest increase in the treatment groups were those pertaining to self-help skills such as 'eating', 'toilet use' and 'dressing and undressing'. These skills were considered necessary and important by the parents for the development of their intellectually disabled children. Hence, the concentration of parents' efforts on training their children these skills.

Other variables in independent functioning such as 'care of clothing', 'cleanliness', 'travel', and 'other general independent functioning' did not reveal a marked increase in the posttest scores in any group. This could be attributed to a number of factors. Firstly, the duration of 8 months was insufficient for all skills of 'independent living' to be dealt with. The second factor was parents' own assessment of the importance and necessity of

such skills in the development of their children. Although the skills of 'care of clothing', 'cleanliness', 'travel' and 'other general independent functioning' are also self-help skills. parents did not consider these skills as burdensome if they were to perform them. In discussing with parents the importance of all the skills listed for independent living, parents had verbalised that the above four skills were not their priorities in training; what they considered as priorities and of necessity were skills pertaining to management of personal need of their intellectually disabled children by themselves.

Fron the parents' responses, it was found that although they come from different walks of life and having different educational attainment, there was common consensus regarding types of skills needed by their intellectually disabled children for independent functioning. Where this is concerned parents would spend time in training their children these skills as long as they have access to information on techniques of teaching these skills. Hence the better gain scores of these children in 'eating', 'toilet use' and 'dressing and undressing'.

It can thus be said that skills which the parents considered as necessary for the development of the children were motivating factors in parental involvement in the training of their disabled children. With information gained on how to handle their children and demonstrations on the actual teaching techniques of specific skills, parents were able to have positive interaction with their children. The individualised manner in which the training was conducted and parents' participation in the decision-making process regarding the skills to be focussed enabled parents to be partners in the training of the intellectually disabled children. Throughout the sessions parents' opinions and comments were solicited thereby elevating them from the position of passive recipients to active partners in the whole rehabilitation process.

Differential Effects of the Three Modes of Training

The results of the ANCOVA (**Refer Table 1-b**) denotes a significant difference in the posttest mean scores of the children whose parents underwent the three modes of training

when compared to the control group. Duncan's Test was conducted to determine which of the groups was significantly different. Duncan's Test **(Refer Table 1-c)** showed a significant difference between Group A and Group B as well as between Group A and Group C. Of the three modes of training, mode A was the most effective since the total posttest mean score registered by the children for independent functioning was the highest (58.50) compared to GroupB (46.36) and GroupC (42.00). The score of the control group, however, was 27.83.

The finding is important because out of the three modes of training, only mode A considered the home environment of the child. Home environment is important because in most cases the school situation is different from that in the home; yet skills learnt in the school or centre had to be transferred to the home for generalisation to take place. This would entail modification of techniques and materials used if the home situation is different from the school setting. Focus on this is important so that parents could be helped to continue teaching their children even though the materials used and the physical set-up were not similar to that found in the training sessions. Besides other family members would also be exposed to training the disabled member in the family thereby lessening the burden of the mother or father.

Another element in mode A of training is the focus on the well-being of the parent trainer, in most cases, the mother. In the regular meetings between the researcher and the mothers, relationship-building was also focussed. The home visit feature of mode A had the element of direct psychological support apart from purely imparting teaching techniques. Concern was made to relieve stresses faced by the parents and family as a whole. During the home visits, parents were asked about their problems and in most cases were able to confide their problems freely which they would not be able to do so in a group setting during the training sessions at the centre. The home visits would give the parents the opportunity to vent their feelings, seek clarification and answers to the many questions and problems faced by them and at the same time build a positive attitude towards disability of their child. For unless parents' questions were answered, fears and

anxieties allayed and problems minimised, there was no way that they could be motivated to be partners in rehabilitation.

Thus we see that mode A of the training models,with its focus on the three main components, namely, the problem, that is, the child's specific skills development need and accompanying teaching techniques, the environment and the psychological frame of the parent trainer was effective in motivating parents to be involved in the training of their disabled children.This model which had the element of teaching techniques for skills development of the child as well as the focus on the "person" in the parent trainer, was effective as it took into consideration the principle that development of the intellectually disabled child is only possible if the environmental factors, both physical and psychological are also brought into play. It is safe to point out that the development of the intellectually disabled varies proportionately with the parents' attitude and understanding towards his/her disability. Parents can either stall or accelerate the child's performance. Thus for partnership to take place, the development of a positive mental attitude in the parents is of paramount importance. Such attitude can be initiated through the professional's sensitivity and understanding towards parents' feeling, fears, needs and anxieties and meeting them at their level. This is possible when professionals meet parents individually in their homes at a time convenient to them.

Apart from teaching parents individually at the centre and at home mode A also provides a means for parents in the same predicament to meet one another and not feel alone. Interaction with one another would provide support and sustain parents' involvement in the training of their children.

The results also showed that mode B of training could be useful in terms of training parents to teach skills whereby modification of the physical aspects of the environment of the child does not come come into play. Such skills include 'eating', 'dressing and undressing' as well as behaviour modification techniques. As long as techniques of teaching each skill was shown to parents and opportunity for practice on their individual

child under the supervision of the professionals, parents would be able to train their child. However, two factors have to be considered. These are parents motivation and support. Since mode B of training was also held in a group setting parents were able to interact and observe one another. Through this parents were able to derive support and encouragement to train their individual child. Thus the motivation to continue their partnership with the researcher in training their child despite difficulties was continued even though the researcher did not meet them in the privacy of their homes.

It can be deduced that the teaching of a skill whereby the main apparatus/equipment used remains the same irrespective of the physical environment, the element of home visit is not crucial. As long as parents have exposure to demonstration of techniques of teaching specific skills, role modelling and support, they would be able to teach their child. This concurs with the study by Mash et.al. (1973) and other behaviour modification projects conducted in the west (see Howlin,1989; Stevenson et. al.,1982; Bidder et. al.,1975; Whelan et. al., 1982).

Mode C of training was purely aimed at educating parents on the techniques of helping their children to develop self-help skills. Parents were exposed to information of handling their children during the lecture sessions. The results show that this mode had minimal effect on the skills development of the intellectually disabled children when compared to the other two modes(see Tables 1-a and b). This was because parents had to translate into action what they had learned in the lectures. Help was only given in the form of task analysing the skills to be covered but not on how these activities were conducted. However, whether parents could do so or not very much depended on the parents own will-power, their attitude towards training their child and their ability to individualise the techniques discussed to suit their child and home situation. Hence the majority of the parents in this mode of training (that is, worksop and lectures) did not carry out proghrammed teaching on their own as intended. This concurs with the findings of Salzburg and Vilani (1983); Hornby and Suiza(1984). Hence this form of training parents for partnership role in training their intellectually disabled children is not effective.

Conclusion

The results show that parents can be partners with professionals in the rehabilitation of the intellectually disabled child. However, this is only feasible if relevant information and training are given to parents.

Knowledge of the techniques of teaching specific skills alone is not enough. Parents must have positive attitude towards training their child. A focus on the psychological well-being of the parents is important to facilitate and motivate parents to be partners in rehabilitation.

Practical and on-hand training through role-modelling is an effective mode in teaching parents to train their disabled child.

Parents' participation on equal footing with the professional worker and an informal social environment are considered crucial for the success of partnership in rehabilitation of the intellectually disabled child

Hence, for partnership with parents to take place, the model proposed should comprise the elements of specific skills needed by the child, the demonstration of techniques of these skills, a supportive and positive environment and the psychological well-being of the parents.

In short, the model should have a combination of the emotional-supportive and educational component, with emphasis, not only on dissemination of information but also on individualised practical demonstration of techniques for acquisition of specific skills as well as the emotional well-being of the parents. However it calls for considerable effort on the part of the professionals and parents. For smooth implementation to take place,

consideration has to be made on the various elements underlying it. This would include sensitivity of the professionals towards the parents or the parent-child system, mutual respect, sharing of information and skills, sharing of feelings, sharing the process of decision-making and recognising the individuality of families and the uniqueness of the intellectually disabled child. Only then could parents be effective partners in the whole rehabilitation process.

REFERENCES

Altman, K. and Mira, M. (1983). Training Parents Of Developmentally Disabled Children. In J. Matson and F. Andrasik (eds). *Treatment Issues And Innovations In Mental Retardation.* (pp. 303-372). New York: Plenum.

Bidder, R.T., Bryant, G. and Gray, O.P. (1975). Benefits To Down's Sydrome Children Through Training Their Mothers. *Archives Of Disease In Childhood*, 50, 383-386.

Bijou, S.W. (1988). An Overview Of Early Intervention For Developmentally Delayed Children In *A Challenge To Potentiality The Vision Of Early Intervention For Developmentally Delayed Children.* Proceedings of 1988 International Portage Conference, Tokyo, Japan.

Bronfenbrenner, U. (1977). Toward An Experimental Ecology of Human Development. *American Psychologist*, 32, 513-531.

Cunningham, C.C. (1985). *Working With Parents: Framework For Collaboration.* Milton Keyners: Open Univ. Press.

Fredericks, H.D., Baldwin, V.L. and Grove, D. (1976). A Home Centre Based Parent Training. In D.L. Lillie, F.L. Trohanis and K.W. Goin (eds). *Teaching Parents To Teach.* New York: Walker

Heifitz, L.J. (1977). Behavioural Training For Parents Of Retarded Children: Alternative Formats Based On Instructional Manuals. *American Journal Of Mental Deficiency*, 82, 194-203.

Hobbs, N. (1975). *The Parents And The Professional. The Futures of Children.* San Francisco: Jossey-Bass.

Hornby, G. and Siuiza, N.N. (1984). Behavioural Group Training With Parents Of Mentally Retarded Children. *Journal Of Mental Deficiency Research*, 28, pp. 43-52.

Howlin, P. (1989). Changing Approaches To Communication Training With Autistic Children. *The British Journal Of Disorders Of Communication*, 24, (2), 154-160.

McConachie, H. (1986). *Parents And Young Mentally Handicapped Children: A Review Of Research Issues.* London: Groom Helm.

Jowett, S. and Baginsky, M. (1988). Parents And Education: A Survey Of Their Involvement And Discussion Of Some Issues. *Education Research*, 30, (1), pp. 36-45.

Kravetz, S., Katz, S. and Katz, S. (1990). A Goal Directed Approach To Training Parents Of Children With A Developmental Disability. *The British Journal Of Mental Subnormality*, vol.XXXVI, Part I, January 1990, No.70, 17-29.

Mash, E.J. Lazere, R., Terdal, L., and Garner, A. (1973). Modification of Mother-Child Interactions: A Modeling Approach for Groups, *Child Study Journal*, 3, pp.131-143.

O Dell, S. (1974). Training Parents In Behavior Modification: A Review. *Psychological Bulletin*, 81, pp. 418-433.

Salzburg, C. and Villani, T. (1983). Speech Training By Parents Of Down's Syndrome Toddlers: Generalization Across Settings And Instructional Contexts. *American Journal Of Mental Deficiency*, 87, pp. 403-413.

Smith, T. (1980). *Parents and Preschool.* London: McIntyre. @BIB = Tharp, R.G. and Wetzel, R.J. (1969). *Behaviour Modification In The Natural Enviroment.* New York: Academic Press.

Stevenson, P., Martin, B. and Stevenson, J. (1982). The Evaluation Of Home-based Therapy For Language Delayed Pre-School Children In An Inner City Area. *Journal Of Disorders Of Communication*, 17 (3), 141-148.

Whelan, E. and Speake. B. (1982). *Learning To Cope.* London: Souvenir Press.

Zaman, S.S. and Islam, S. (1988). Development Of Portage Services in Bangladesh. In *A Challenge Of Potentiality: The Vision Of Early Intervention For Developmentally Delayed Children. In Proceedings 1988 International Portage Conference* in Tokyo July 29-21, 1988.