

A GOAL DIRECTED APPROACH TO TRAINING PARENTS OF CHILDREN WITH A DEVELOPMENTAL DISABILITY

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INTRODUCTION

The purpose of this paper is to describe the rationale and techniques of a general approach to setting up a series of related training programmes for parents of children with a developmental disability. Many professionals concerned with the counselling, education, and training of individuals with a developmental disability advocate training parents to deal effectively with the consequences of their child's disability. (Helm and Kozloff, 1986; McConkey and Jeffree, 1975). This treatment philosophy appears to be motivated by three related issues. These issues are the functional utility of parent training, the role of socialisation agent that societies generally ascribe to parents, and the parent and family as additional clients of the professional.

Parent training is considered to possess functional utility because the structure of the parent-child relationship places the parent in a position to be an effective and efficient means of improving the behaviour of the child with a developmental disability. Hobbs (1975) argues that in terms of intensity, frequency, and duration of contact, parents have a very significant advantage over the professional. Many intervention techniques require highly frequent and regular intensive interactions. Since parents are more available than professionals, the training of parents as caregivers has been proposed as a way of increasing the efficacy of these interactions (Altman and Mira 1983; Cunningham, 1985). Parents are also in an optimal position to increase the probability that solutions which have been worked out in the therapist's office or the classroom 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 therapist 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). Finally, participation in a supervised group training programme can provide the parents with a more realistic perspective regarding their children's limitations and capabilities (Menolascino, 1977).

Most societies assign to parents the role of the socialisation agents of their children. This normative role is especially prescribed in such sensitive areas as

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interpersonal relations and sexual behaviour. Thus, training parents and modifying parent attitudes so that they can fulfill their role more effectively and appropriately should be more harmonious with social norms than would be transferring a major portion of the parental role to the professional (Hobbs, 1975).

Furthermore, involving parents in the training of their developmentally disabled children may focus attention on problems that may otherwise be overlooked when therapeutic effort is invested mainly in treating the child with the disability. Since the developmentally disabled child develops as an integral part of a family system, his or her problems cannot be meaningfully isolated from the manner in which the family modifies its functioning in response to having a member with a disability (Wikler, 1986). The child's developmental successes and failures may impact upon the parents' experiences of family cohesiveness and control in the same manner as the parents' attitudes and behaviour influence the child's sense of acceptance and competence. Fathers and mothers of children with mental handicaps often experience severe disappointment, stress, a sense of loss and a decline in self esteem (Birenbaum, 1971; Harris, 1984; Menolascino, 1977). Wikler (1981) maintains that the periods of crisis and adjustment experienced by the parents are related to the developmental stages of the child and the family. Family intervention programmes may be able to modify these bidirectional family interactions so as to increase rather than to decrease family coherence and competence. According to this argument, the family as well as the child with the disability can be considered the professional's client.

Thus, an important facet of parental training programmes is the feeling of competence and control that parents can obtain from participating in such programmes (Heifetz, 1977). The provision of information and specific skills for dealing with their children's problems and inappropriate behaviour can reduce the parents' anxiety and frustration. Parents learn that they are capable of effectively dealing with the special problems of a child with a developmental disability (Tavormina, 1975).

Due to the persuasiveness of the above arguments, over the last twenty years, a variety of training programmes for parents of children with developmental disabilities have been carried out and a number of critical reviews of these programmes have been published (Baker, 1976; Cunningham, 1985; Helm and Kozloff, 1986; Hornby and Singh, 1983). The general conclusion of these literature surveys is that these programmes have improved the quality of life of the parents and children who have been involved in them. Although Helm and Kozloff (1986) point out numerous defects in the studies undertaken to evaluate these programmes' effectiveness, *their general impression is that "they seem to affect most parents in a beneficial way" and that "beneficial changes in the parents (as defined by the goals of the training programme) are usually followed by beneficial changes in their children (p. 12)."*

Despite the general satisfaction with these programmes, they have been criticised from two apparently contradictory perspectives. The core of one set of criticisms is the claim that most parent training programmes are based on an overly atomistic and static model of human behaviour and development (Helm and Kozloff, 1986). This model artificially fragments human behaviour into a number of oversimplified units and thereby, pays insufficient attention to the variety of continuum that could be used to select target behaviours and problems.

It also tends to focus on the inadequacies of the child with the disability and neglects the perceptions, coping strategies, and interaction patterns of the family and the extended social context within which the family functions. Consequently, according to this critical stance, the research methodology constructed to evaluate these programmes mainly concentrates on the changes that have been specified as their goals and does not examine their impact on the perceptions and interaction patterns of the family.

These programmes have also been criticised from the point of view of the normalisation principle (Wolfensberger 1980). One of the innovative implications of the normalisation principle is that the nature of the intervention techniques applied to the problems of persons who are disabled should be as culturally and socially normative as possible. Setting up parent training programmes exclusively for parents of children with developmental disabilities may contribute to the anormalisation of both the child and the child's family. In addition, confining the professional's direct interventive role to the clinic or classroom may limit the dependency of the family and child on professional services whereas expanding this role to include the home and community may increase this dependency.

On the one hand, the former criticisms imply that most parent training programmes are not sufficiently broad and pervasive to deal with the complexities facing families with a child with a developmental disability. On the other hand, the latter criticisms seem to be concerned that the very notion of exclusive training for parents of children with developmental disabilities may broaden the impact of the disability rather than curtail it.

Goal Directed Training Approach

The goal directed approach for setting up parent training groups that will be described in this paper may be an appropriate response to the above divergent criticisms. This approach was implemented in a research and service project entitled **A School for Parents of Children with a Developmental Disability** (Katz, et al., 1987). The four main features of this approach which is detailed in Table I are:

1. the critical stages of the family life cycle with which the groups help parents to deal,
2. the goals which each of these stages set for families and which the groups help parents to attain,
3. the individual and group processes and techniques which the groups implement to help parents to attain these goals, and
4. the specific and general outcomes which serve as the indices of the effectiveness of the groups' efforts.

TABLE I

An Outline of the Goal-Directed Parent Training Approach of Parents of Children with a Developmental Disability.

Approximate Chronological Stages of The Family Life Cycle	Goals of the Family Life Cycle	Group & Individual Process	Outcomes
5 years or less	Acceptance of the disabled child. Sensory, motor and cognitive development. Physical independence.	Affective counselling. Family therapy. Infant stimulation. Pre-School preparation. Behaviour modification for self-help skills.	Attitude change. Family satisfaction. Accelerated development. Independence in self care.
5 to 13 years	Child's self acceptance. Physical, personal and social independence and adjustment in school. Reducing family stress. Improving the quality of the parent/child relationship.	Training in parenting. Behaviour modification for self-help and social skills. Cognitive training. Interpersonal training. Family problem solving.	Attitude change. Child's self-esteem. Independence in self care. Personal and social adjustment. Satisfaction with school. Academic achievement.
13 to 19 years	Appropriate interpersonal behaviour. Attainment of personal, familial and social goals.	Interpersonal skill training. Sex education.	Parent and child acceptance of child's sexuality. Accurate and appropriate sexual and social knowledge and behaviour.
19 years and older	Independent living. Attainment of vocational and economic goals. Transition from the world of school to the world of work.	Genetic and marital counselling. Consumer training. Vocational counselling. Consumer advocacy. Interpersonal and vocational skill training.	Community integration. Independent living outside of parents' home. Marital vocational and economic satisfaction.

Specific parent training groups that are goal directed and focus upon the tasks which normally confront parents and children at different stages of the family life cycle can be set up on the basis of the parameters described in Table I. Thus, the family life cycle provides guidelines for selecting the goals for the parent training groups and the individual and group processes and techniques most appropriate for attaining these goals. In addition, viewing the family life cycle as a series of goal directed projects to be accomplished by means of parent/child interactions suggests criteria which can be used to assess the effectiveness and efficiency of the parent training groups.

The goal directed approach is a partial response to the criticism that the model of human behaviour and development applied by most parent training programmes "does not accurately depict the complex hierachial and sequential organisation of behaviour as it develops in its social and physical contexts" (Helm and Kozloff 1986 pp. 2-3). One can argue that the behavioural and social sciences have yet to provide the practitioner with a comprehensive model of human behaviour on which clinical practice can be firmly based (Kanfer and Schefft, 1988). In lieu of a theoretically valid model that is both sufficiently complex and practical, the goal directed approach provides a pragmatic rationale for selecting intervention techniques that may potentially achieve a number a related objectives. This approach has been influenced by both sophisticated theories of human development (Erickson 1950) and practical heuristics (Haley 1973) that use the family life cycle as a basis for describing human problems. In addition, there is some evidence that at different stages of the family life cycle, parents of children with a developmental disability experience crises and require different kinds of psycho-social interventions (Suelzle and Keenan, 1981; Wikler, 1986).

The goal-directed training approach conceptualises the family life cycle as a developmental series of goal-directed projects to be carried out within the context of parent child interactions and focuses attention both on the parents and the child. This developmental series of goal-directed projects also emphasises the qualitatively different goals that emerge at each stage of the family life cycle. Such goal-directed projects can be characterised by specific problems that must be dealt with to obtain the goals, the parental and child skills necessary to cope with these problems, and the emotional and attitudinal atmosphere that is both conducive to the appropriate use of these skills and correlated with the attainment of the goals.

The flexibility of the goal-directed construct allows for the practical and critical resolution of theoretical schisms that may have impeded attempts at parent training. One professional and theoretical disagreement that has received a great deal of attention in the literature on parent training is concerned with whether this training should be psycho-educational or insight-reflective (Cunningham, 1985; Hornby and Singh, 1983:). Another professional difference has to do with the relative efficiency of group techniques of parental training as compared to individual techniques. (Baker, 1976). General vs specific aims is another controversial issue related to parent training (O'Dell, et al. 1977).

Table I provides a framework for generating sets of interventions that combine aspects of the above theoretical positions. These sets can be used for choosing appropriate intervention and assessment methods for the parent training groups. The parent training programmes included in these sets can take advantage of counselling techniques that are sometimes presented as if they were mutually exclusive. Thus, some of the groups set up according to the goal-directed approach can use a combined group-individual technique. In keeping with this technique, basic attitudes can be clarified and basic parenting skills acquired in a group setting whereas the group leader can observe and supervise the application of the group training experience in the home. The selection of an evaluation methodology can combine the assessment of specific and general changes in the behaviour and attitudes of the children and parents. It can test hypotheses derived from such theoretical statements as the assumption that positive emotional and attitudinal

changes may be the by-product of parents' learning specific skills. In this way, the goal-directed approach offers practical guidelines for setting up and evaluating parent training programmes while at the same time providing data for testing the validity and usefulness of a number of comprehensive statements about human behaviour and development.

Although the goal-directed approach can be used to set up parent training programmes at various stages of the family life cycle, the extent of any family's participation in these programmes can be as limited as that family desires. These training programmes can be limited by a temporal format that specifies the duration and number of group meetings or home visits. A family may participate in one programme and only return for additional training if developmental changes create stresses that require such training. Most of the training programmes can be established in the community in co-operation with the existing service agencies that the parents use. Furthermore, goals can be selected for the groups that entail the parents involvement in such social and private agencies as nurseries, kindergarten, schools and local community services to further the integration of the person with the disability within the community. In this way, the goal directed approach may reduce the anormalization effects that some critics have attributed to parent training exclusively for parents of children with a developmental disability.

Goal Directed Parent Training Groups

As mentioned above, the School for Parents of Children with Developmental Disabilities has used the goal-directed approach to set up a number of parent training programmes. Detailed descriptions of these programmes together with the results of evaluations of aspects of these programmes' outcomes have been published (Katz et al. 1987; Katz et al. 1989). This paper will briefly describe a number of programmes as examples of how the goal-directed approach can be applied. All of the groups to be described except for the interpersonal skills and sex education groups used a combined individual-group technique.

Early Infant Stimulation Group. The principle goal of these groups was the improvement of the sensory, motor, and cognitive development of the Down syndrome infants whose parents participated in the groups. In addition, participation in these groups was expected to improve the health and physical condition of the children and increase their family's acceptance of them. By means of the group-individual format and a workbook especially prepared for these groups, mothers learned how to work on their infants' sensory, motor, and cognitive development, using a set of progressive early infant stimulation exercises. In addition to learning observation, evaluation, and training skills, the mothers also had the opportunity to raise other issues and experiences related to parenting a Down syndrome child. Problems of daily health and physical care of Down syndrome infants were also dealt with in terms of the needs of the particular mothers who participated in each group.

The effectiveness of these groups was evaluated in terms of their principle goal of improving sensory, motor, and cognitive development. The Gesell Infant Developmental Scale was administered to the Down syndrome children whose mothers participated in these groups. This scale was administered at the initiation of each group, approximately 6 months later, and 3 months after the group terminated. The children who participated in these groups were then tested every

year until the present. In addition there was a control group which included children with Down syndrome whose parents had not participated in an early infant stimulation programme. These children were randomly chosen from referrals to a child developmental centre in the Tel Aviv area. The criteria for selection was that these children had also been evaluated over a period of at least 3 to 4 years from the first year of life.

Figure 1 depicts the curve of the group of children whose mothers participated in the early infantile stimulation group, and the curve of children whose mothers did not participate in the early infantile stimulation group.

Figure 1

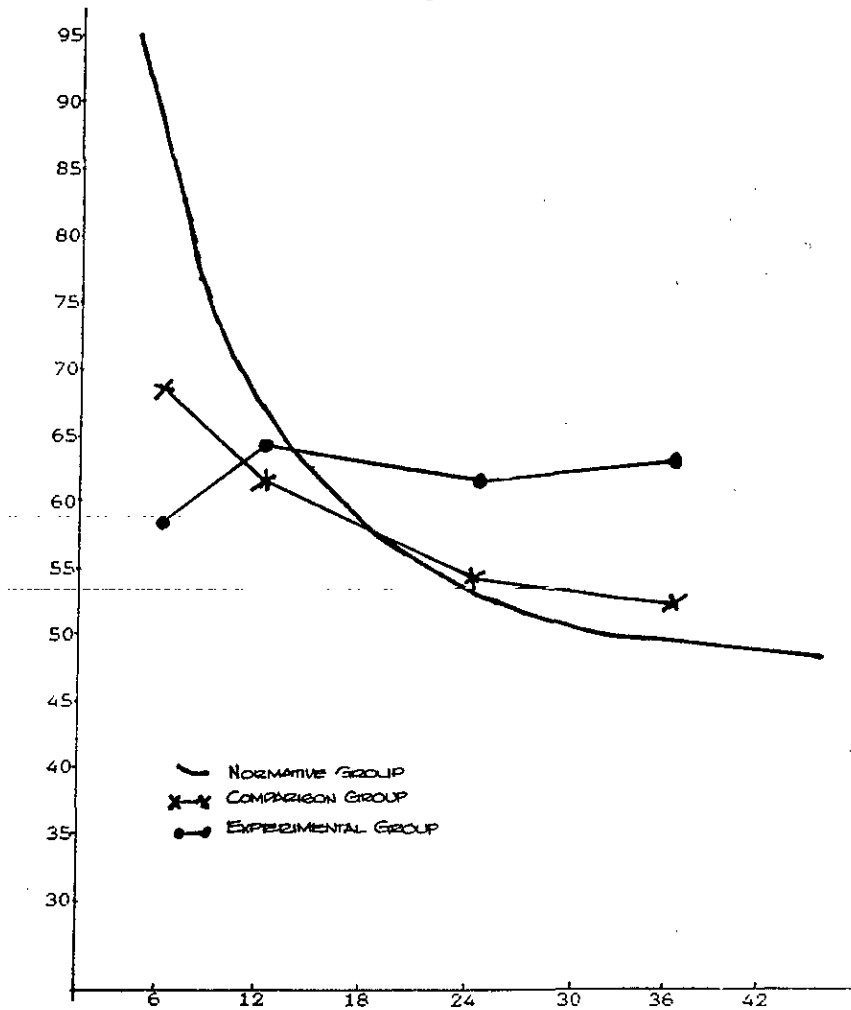


Fig. 1
Mean D.Q.s for Experimental and Comparison Groups
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In addition a normative curve for children with Down syndrome taken from Canning and Peuschel's (1978) report is also included as a third comparison group. This normal curve reveals the deceleration of DQ/IQ that has been found to be characteristic of children with Down syndrome. As can be seen from the graph, the curves formed by the average DQ's of the control groups is similar to the normative curve and these two curves indicate a pattern of deceleration. Whereas these curves indicate a pattern of deceleration, the curve of the average DQ's for the experimental group remained relatively stable over the evaluation period.

Self Help Skills Behaviour Modification Group. The goal of these groups was to increase the functional independence of the mentally handicapped children whose mothers and fathers participated in them. Functional independence included the children's ability and readiness to feed and dress themselves and to care for their personal hygiene. During the group sessions, the parents learned the principles and techniques of behaviour modification and how to use these principles and techniques to improve their children's self care. A workbook was prepared for use in teaching the parents which included fourteen self help behaviour modification programmes based on the principle of learning by successive approximation. On completion of the group sessions, the parents began working on the training programmes with their children at home where their work was supervised by the group leader.

A multibaseline- multibehaviour method was used to assess the effectiveness of these groups. One of the skills that these groups imparted to the parents was accurate observation of their children's behaviour. Therefore parents observations of improvement in their children's self care behaviours were the criteria for these groups' attainment of their goal (Katz et al., 1987).

A self-help skill assessment checklist developed by Watson (1973) was used to assess the groups' impact on the children's achievement of independence. Each of the 14 skills taught is broken down into a series of behavioural steps. The parents rated the quality and frequency of each step on separate 5 point rating scales. These ratings were initiated immediately prior to the onset of the parents' training of their children and were carried out an additional 4 to 5 times during this training. The product of the quality and frequency ratings provided the proficiency level for each step in the behavioural chain comprising the skills.

Figure 2 presents graphs of 3 children whose parents participated in the project. Each graph represents a child's progress in the skills taught by the parents who participated in the group. The achievement score of each graph consists of the product of the observed frequency and rated quality of the behaviours selected by the parents of each child. The abscissa of each graph represents consecutive rating periods. In keeping with the multiple baseline research design, the durations of the baselines for the different behaviours differed. Training was generally initiated between the second and fourth rating period for the different behaviours. The sixth rating was carried out in the home after the termination of the formal training programme.

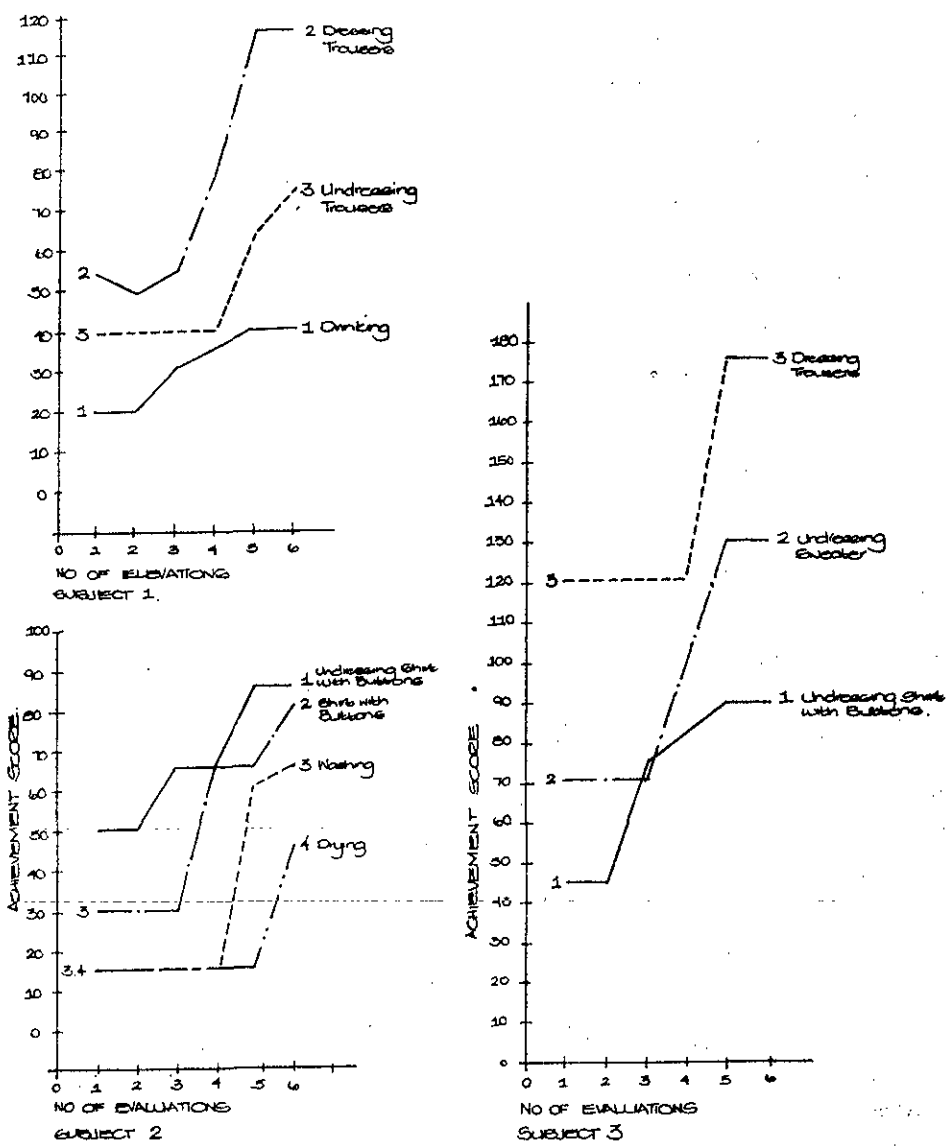


Fig. 2
Subjects Performance On Self Help Skills

As can be seen from the graphs in Figure 2, the subjects showed consistent improvement of the skills at the point at which treatment procedures were initiated. The improvement for the three subjects is consistent for all the skills and shows a similar pattern of acceleration with the initiation of the training programme irrespective of the skills taught. The follow up and observations and ratings that were carried out after the formal training had been terminated indicated that the

children maintained the behaviours that they had learned. The graphs of the remaining children whose parents participated in the study tended to be quite similar to these three graphs.

Behaviour Problems Behaviour Modification Group. The goals of these groups were reducing the frequency of behaviour problems emitted by the child with the developmental disability and improving the quality of the parent child relationship. Although these training programmes were set up for parents of children with a variety of developmental disabilities, each group was relatively homogenous with regard to the children's disability and age. The groups included parents of children with a mental handicap, learning disability, and autistic behaviour. Two counselling approaches were used with these groups of parents. These approaches differed with regard to the degree to which they adhered to behaviour principles and techniques. The group leaders of the groups of parents of mentally handicapped or autistic children used a relatively strict behavioural modification approach whereas the group leaders of the groups of parents of learning disabled children combined behaviour modification techniques with family therapy and counselling and the provision of practical information about the nature and impact of specific learning disabilities. Home visits were used both as an opportunity to supervise parents' application of what they learned in the group session and to observe and assess family relationships and to guide the families in improving these relationships.

A behaviour checklist including 46 behaviour problems was constructed for use with these groups. Parents filled out this checklist prior and subsequent to their participation in the groups. Thus, one measure of these groups' effectiveness was the reduction in the frequency and severity of the parents' reports of these problems. Another measure of these groups' effectiveness was family satisfaction as reported by the parents on a 14 item scale (Katz et al., 1987).

The before and after means and standard deviations of the product of the frequency and severity of the behaviour problems for all three types of disability are shown in Table II. The before and after means and the standard deviations for the measures of family need satisfaction for these children's parents are shown in Table III.

Table II
Before and after means and standard deviations of frequency and severity of behaviour problems for behaviour modification groups

	Mentally Handicapped		Autism		Learning Disabled	
	M	S.D	M	S.D	M	S.D
Before	3.73	0.93	4.62	1.40	2.70	0.86
After	3.18	1.05	3.01	0.42	2.90	0.68
F	7.36		4.88		0.93	
P	0.03		0.11		0.37	

As can be seen from Table II, for the mentally handicapped and autism groups, the mean products of the frequency and severity of the behaviour problems were lower after the termination of the groups than they were at the onset of the groups. However, only in the case of the product of the frequency and severity of the inappropriate behaviours of the mentally handicapped children was a statistically significant difference between the before and after measures attained.

TABLE III

Before and after means and standard deviations for measures of Family Need Satisfaction for Behaviour modification groups.

	Mentally Handicapped		Autism		Learning Disabled	
	M	S.D	M	S.D	M	S.D
Before	2.79	0.36	2.80	0.28	3.16	0.47
After	2.79	0.32	2.70	0.25	3.08	0.36
t		0.00		0.94		0.34
P		0.99		0.40		0.57

Examination of Table III indicates that the level of family satisfaction at the termination of the groups was similar to the level of family satisfaction at the onset of these groups. Thus the difference between the levels of the combined reports of the mothers' and fathers' satisfaction was not statistically significant.

Interpersonal Skills and Sex Education Groups. The principle goal of these groups was to positively effect changes in parent attitudes towards the sex education of the adolescent with the developmental disability. In addition, parents were provided with the parenting skills that are considered helpful in dealing with their adolescents' interpersonal relationships. Each group session was devoted to a specific topic related to training in interpersonal relations and sex education for persons who are developmentally disabled.

Since a principle goal of these groups was attitude change, two attitude scales were used to assess the impact of participation in this parent group training programme. One scale was a direct measure of the parents' attitudes towards the sexuality of persons who are mentally handicapped. The other scale consisted of three direct measures of the parents' attitudes towards providing a person with a mental handicap information concerning his or her sexuality. The means and standard deviations for the attitude measures are presented in Table IV.

TABLE IV

The Means and Standard deviations for the attitude towards sexual information and the sexuality of Mentally Handicapped persons.

Variable	Before		After		t	P
	M	S.D	M	S.D		
Information A	0.68	0.14	0.67	0.13	0.24	0.41
Information B	0.78	0.13	0.76	0.16	0.39	0.35
Information C	0.76	0.15	0.70	0.18	0.96	0.20
Attitude towards Sexuality	0.62	0.15	0.77	0.13	2.51	0.02

The results in this table indicate that the parents' attitudes toward the sexuality of the mentally handicapped person was more positive at the termination of the group than it was at its onset. None of the other results were statistically significant.

The parents who participated in the groups and the community agencies that co-sponsored and hosted the groups generally seemed satisfied with the group parent training programmes. This satisfaction was reflected by the generally high overall attendance rate for the groups and by the requests of both parents and agencies for additional parent groups. Parents seemed especially to appreciate the structured assistance offered by the groups that applied problem focussed techniques to achieve relatively specific goals.

Results obtained by observation schedules and self report measures seem to reinforce the more subjective impression that the more structured groups were more effective in attaining their more specific goals. These schedules and self report measures seem to indicate that parent training groups with more vaguely defined goals were less successful in dealing with these problems. Despite some negative findings, formal and informal evaluations of the impact of the different groups set up using the goal-directed approach has been encouraging and has provided critical guidelines for refining and expanding the training provided by these groups.

SUMMARY

This paper describes the rationale and techniques of a general approach to setting up a series of related training programmes for parents of children with a developmental disability. The goal directed approach described in this paper offers practical guidelines for setting up and evaluating parent training programmes and was implemented in a research and service project entitled A School for Parents of Children with a Developmental Disability. It also can provide data for testing the validity and usefulness of a number of comprehensive statements about human behaviour and development. This approach can also be viewed as a partial response to divergent criticisms of existing parent teaching programmes.

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