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Abstract

This paper describes a training program for enhancing parent support networks by improving parents interpersonal problem solving skills. It discusses the rationale for such a program which is to avoid making the child with the disability the scapegoat. It looks at the multiple stresses which confront parents and which could be alleviated by social support networks. **Keyword: Families**

Enhancing Social Support for Parents of Developmentally Disabled Children: Training in Interpersonal Problem Solving Skills

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Abstract: This paper is a description of the rationale for and implementation of Interpersonal Problem-Solving Skills Training with parents of developmentally disabled children. It reviews the multiple stresses which confront these parents and indicates the important role that social support networks can play in helping them cope more effectively. A training program for enhancing parents' support networks by improving their interpersonal problem-solving skills is described. Overall, the training seemed to be effective and provided a much needed supplement to the package of helpful services now made available to parents of the developmentally disabled.

Families with developmentally disabled children have been the focus of a considerable amount of research over the past 30 years. In general, this work has demonstrated that these families experience a greater level of stress when compared to similar families with normal children. The specific types of stresses documented for families of the developmentally disabled are myriad and include periodic grief and chronic sorrow, strain resulting from the constant unrelieved burden of caretaking, shifts in the role expectations for individual family members, marital conflict, social isolation, sibling adjustment problems, and financial burden (Boggs, 1979; Davidson & Dossier, 1982; Farber, 1959; 1968; Holt, 1958; Menolascino, 1977; Mercer, 1966; Wikler, 1981; Willer, Intagliata, & Atkinson, 1979).

These stresses are a matter of concern for several reasons. They may, for example, endanger the physical health, mental health, and overall life quality of individual family members. They also place great strain on the marital bond and, when not managed effectively, may contribute to separation and/or divorce. Finally, these stresses often detract from the capability of the family to provide quality care to their developmentally disabled child and, in many cases, are the reason why parents request out-of-home placement for their child.

In response to the obvious needs of families of the developmentally disabled, service providers and parents' groups have developed and offered a wide range of supportive services and interventions for families. These include (a) information and referral services that are designed to increase parents' knowledge about developmental disabilities and their awareness of available services (Matheny & Vernick, 1969; Wolfensberger, 1967); (b) self-help parent groups which reduce parents' sense of isolation and uniqueness and provide them with much needed support by offering them the opportunity to share their feelings and experiences with other persons facing similar stress (Davidson & Dossier, 1982; Porter, 1978; Weber & Parker, 1980); (c) individual and/or family therapy to help family members to better understand and cope with their stress and negative emotions related to their developmentally disabled child (Cummings & Stock, 1962; Mandelbaum, 1967; Solnit & Stark, 1961); (d) training programs in behaviour modification techniques to assist

parents in teaching skills and managing behaviour problems (Bricker & Bricker, 1971; Roose, 1972); and (e) respite care to relieve parents from the physical exhaustion and continued psychological burden of caring (Wikler, Hanusa & Stoychef, 1982).

The common thread that ties most of these intervention strategies together is that their focus is usually either directly or indirectly on the developmentally disabled child. For example, in therapy or skills training settings, rather than taking into account the needs and problems of family members that may be unrelated to the developmentally disabled child, many counsellors and trainers focus their attention on helping parents to deal with their feelings regarding having a disabled child or on advising them how to manage their child's behaviour more effectively (Hill, Raley & Snyder, 1982). Even respite care, which seems to be a service directed to meet parents' own needs, is typically portrayed as helpful to parents primarily because it relieves the stress "caused by their child". Thus, not unlike families of developmentally disabled children who have been described as making their disabled children the "scapegoat" by directing an inordinate amount of activity to them (Ro-Trock, Kostoryz, Corrales & Smith, 1981), many of those who work with these families have also placed their primary focus on the child or on relieving the stress created by the child.

This observation is in no way meant to suggest that the supportive interventions discussed above are not helpful to parents and families. However, while they help families to meet some of their needs, they neglect to address the fact that a considerable amount of the stress that parents report results from the difficulties they have in managing many normal life demands unrelated to their child. These demands are those that most parents face daily regardless of whether they have a developmentally disabled child and relate to the challenges of maintaining a healthy marriage, developing and nurturing satisfactory relationships with extended family members and friends, and dealing with occupational stress. While the added demands of parenting a handicapped child may exacerbate the difficulties of coping successfully with other real-life problems, the use of intervention strategies that focus primarily on the child may not be sufficient for helping parents of the developmentally disabled to alleviate their reported stress. A good illustration of this point is provided by Fotheringham, Skelton, & Hoddinott (1972) who found that the out-of-home placement of a mentally retarded child, who presumably was the cause of the marital stress, did not result in improvement or resolution of the marital difficulties.

Social Support and Stress

In recent years increasing attention has been given to the importance of social support in contributing to physical and psychological health (Cassel, 1974; Cobb, 1976; Caplan, 1974). According to O'Connor (1983), social support is made up of the emotional, informational, and material support provided by persons with whom one has an ongoing relationship and to whom one can turn in times of need or crisis. The availability and provision of such support can be crucial for enabling both individuals and families to remain healthy

and intact when confronted with stressful life events (Drabek & Boggs, 1968; Hill, 1949; Imig, 1981; Polansky, Chalmers, Battenweiser, & Williams, 1979).

As part of the ongoing development of the theory and research surrounding social support, a number of researchers have begun to highlight the need for individuals to have different types of assistance available from their support networks. Weiss (1974), for example, suggested a typology which identified six distinct types of "social provisions" that support networks can offer, all of which individuals may need in order to maintain their personal well-being over time. These provisions include a sense of attachment, a feeling of social integration, the opportunity for nurturance, the reassurance of self-worth, a sense of ongoing reliable alliance, and the opportunity to receive guidance or advice. Other typologies that have been offered identify such distinct types of aid as instrumental support, emotional/social support, and referral/information (Cobb, 1976; Dean & Lin, 1977; Unger & Powell, 1980).

The development of such typologies of social support implies that in order for an individual or family to be able to receive the variety of support that they need to cope effectively with stress, their social network must be comprised of a variety of individuals, each of whom may provide a somewhat unique but needed resource. The different types of relationships required to provide such varied resources might include marriage, friendship, parenting, membership in a club, ties to extended family, and professional or work-related relationships. While an individual or family may not require all of these supportive relationships at any given point in time, it is unlikely that their ongoing or periodic needs for social support can all be met through a single person or type of relationship.

Because parents of developmentally disabled people are under a great deal of stress they could be expected to need and benefit significantly from well-developed social support networks. However, the strains upon and the deficiencies that have been identified in the support networks of families of the developmentally disabled are multiple and significant. They include (1) stress and tension in the marital relationship itself which often diminishes the amount of support the parents can provide each other and may endanger the stability of the marital relationship itself (Frederickson, 1977; Waisbren, 1980); (2) strained or broken relationships with extended family members who could potentially provide the parents with assistance in the care of the child as well as much needed personal emotional support; and (3) breakings in relationships with or isolation from friends and neighbours, also a potential source of important social support (Wikler, 1981).

Of the various family intervention alternatives discussed earlier, the only one that is responsive to parents' needs to increase their available social support is the self-help parent group. Perhaps as a reflection of the pressing need these groups meet, they have been extremely popular among parents of developmentally disabled individuals (Davidson & Dosser, 1982; McCubin, 1979). One reason why they are so popular is that they offer parents a chance to spend time with a very special group of others all of whom share the same types of stress and burden as they do. However, despite the fact that such specialised support groups may help to reduce the social isolation that parents

feel, these groups cannot be expected to provide for all of parents' social support needs.

In order to have a more comprehensive base of social support as a buffer for their stress, parents of developmentally disabled individuals need to be able to relate effectively to other people who do not share their experience of parenting a handicapped child. If, as the research would indicate, they have significant difficulties in relating effectively to many of these persons (e.g., relatives, neighbours, co-workers, friends) they may not be able to avail themselves of the important types of support that only these individuals can provide. To date, however, no intervention for parents of the developmentally disabled has been designed to provide parents with the skills they may require to strengthen and broaden their social support networks.

This paper describes the results of a pilot study conducted to assess the degree to which the interpersonal problem solving skills of parents of developmentally disabled children may in fact be deficient and to assess their responsiveness to a training program designed to enhance their interpersonal problem solving competence. The decision to use this particular approach as a way to assist parents of developmentally disabled children was based on (1) the belief that interpersonal problem solving competence is essential for maintaining and nurturing relationships that can provide these parents with the support they need to cope more effectively with their significant life stress; (2) the indications that parents of developmentally disabled children may be deficient in interpersonal problem solving skills (Ro-Trock et al., 1981); and (3) the convincing evidence linking interpersonal problem-solving skill competence to overall personal adjustment (Larcen, Spivack, & Shure, 1972; Platt & Spivack, 1972; Shure, Newman, & silver, 1970; Shure & Spivack, 1972).

Method

Setting

The setting for the pilot work of training parents in interpersonal problem solving skills was a Developmental Disabilities Service Office in Western New York. this office serves as a single point of entry for services in a four-county region and provides such services as initial intake and assessment of the child and family needs, information and referral, and assistance in obtaining residential as well as other support services (day programs, respite care).

Participants

The participants in this pilot effort were three single parents and one couple. In all, there were five developmentally disabled children living in the four family settings. They included two profoundly mentally retarded young girls (ages 6 and 8), one of whom had additional serious medical problems; two non-ambulatory six-year old girls with cerebral palsy but not mental retardation; and one 18-year old girl with a sever seizure disorder and serious behaviour problems. The parents ranged in age from their late twenties to their early forties and were all high school graduates.

Two other single parents initially indicated an interest in participating in the group but were unable to do so because of their inability to get respite care to enable them to attend. Before they agreed to participate, all participants were interviewed by the group leaders who explained the focus of the skills training group and indicated that participating would entail attending a two-hour training session once a week for a period of 10 weeks.

Measures

Given that the focus of the training program was to enhance participants' problem-solving skills, a measure was needed to assess their skill level in this area both prior to and following the training. The measure utilised was developed by Platt & Spivack (1975) and is called the Means-Ends Problem Solving (MEPS) measure.

This instrument makes use of story stems portraying situations in which a need is aroused in the protagonist at the beginning of the story and is resolved by him at the end. The respondent is required to complete the story by filling in those events which might have occurred between the arousal and satisfaction of the hero's need (Platt & Spivack, 1975, p. 16).

The stories that respondents generate in completing the MEPS measure reflect the way that they typically think about and/or go about solving everyday problems with which they are confronted. The scoring procedure for the MEPS instrument was developed by Platt and Spivack (1975) and involves assessing the number and relevancy of means that the respondents indicate the protagonist uses in order to resolve the problem in each story. A relevant means is counted each time the protagonist engages in a discrete instrumental act that clearly enables him/her to move effectively toward or reach the resolution of the problem. Respondents' scores on this instrument have been shown to be significantly related to their real-life problem solving competence and to their overall level of mental health adjustment (Intagliata, 1978; Platt & Spivack, 1972; Shure, Newman, & Silver, 1970).

During the first training session each participant was asked to complete four separate stories. Two of the stories presented interpersonal problems (e.g., argument with spouse, disagreement with boss), another offered an intrapersonal problem (e.g., depression, nervous anxiety), and the final story presented a problem related to a handicapped child (e.g., arranging for respite care).

Following the tenth and final group session all participants were once again asked to complete four stories relating to two interpersonal problems, one intrapersonal problem and one problem associated with the care of a handicapped child. The first administration of the procedure involved the random selection of four stories from an eight-story MEPS protocol adapted from Platt and Spivack (1975). For the second administration, participants were asked to complete whichever four stories they had not previously been given. All stories, with the exception of those involving a handicapped child,

were drawn directly from the standard MEPS protocol. The two stories involving a problem with a handicapped child were developed especially for this pilot study and were designed to carefully follow the format of the standard MEPS stories.

Description of training

The package of ten training sessions developed for this parent group incorporated a variety of training materials developed by Platt, Spivack, & Swift (1973) as part of a program of interpersonal problem solving (IPS) group therapy for adults and was modelled after a ten-year session IPS training program that the first author had developed for use in an alcoholism treatment program (Intagliata, 1978; 1979). This program is highly structured, actively engages all participants in each session, makes extensive use of role playing and involves regular homework assignments between sessions. Specific didactic materials were also developed and added to the training programming order to better meet the particular needs of parents with developmentally disabled children.

The ten training sessions were designed to teach participants a five-step process for dealing with interpersonal problems. These steps include (a) recognise that you have a problem, (b) define the problem, (c) generate several alternatives for dealing with it, (d) look ahead to the likely consequences of each, and (e) select and implement the alternative that best meets your goals. Specific issues dealt with in the sessions include understanding non-verbal cues about feelings, the importance of slowing down to avoid jumping to wrong conclusions, defining problems in such a way that they can be addressed, involving the "other" person in the problem-solving process, differences in interpersonal problem solving styles and the importance of deciding on your goal before attempting to resolve a problem.

Results

The Group Process

A major objective of this pilot study was to assess the responsiveness of parents of the developmentally disabled to training them in skills that, while useful in dealing with everyday problems, were not directly focused on helping them manage their disabled child more effectively. While the potential relevance of this type of intervention for this population is suggested in the literature, it clearly has not been a need articulated by parents in general, nor, at least initially, by the parents in our training group. Our experience in these sessions, however, confirmed for us that such training met a very real need, at least among the parents in our group,

During our first two group sessions, all of the participants spoke quite freely with each other about the significant grief, stress, and problems that having their handicapped child had created for them and their families. The single parents spoke of the conflicts and tensions that it had caused between them and their ex-spouses and how these conflicts had helped contribute to their

divorces. The married couple spoke in some detail about the problems that their child created for them with their in-laws and other relatives. All group members spoke about the isolation they felt from others who could never really understand them because they did not also have a developmentally disabled child.

When asked to identify and list problems that they experienced daily, most of those listed involved their developmentally disabled child directly (e.g., the incredible amount of time, that he/she requires). Additional problems included marital conflict, depression, and anxiety and strained relations with friends or relatives. However, even for these additional problems the group members agreed unanimously that all were either caused by or could not be solved because of their disabled child. Further, they indicated that if they had not had their child to begin with, they doubted whether they would have any of these problems now. The parents then challenged the idea of our training group because it could not solve the only problem they really had; that is, to make their developmentally disabled child normal.

Over time, as we moved away from the relatively unstructured discussion that took place in the first two sessions and began to get the parents actively involved in interpersonal problem-solving exercises and homework assignments, their intensive focus on their child as their only problem diminished significantly. In fact, from Session 4 on, the vast majority of real life problems that group members volunteered for us to work with no longer involved or were attributed to their children. During one of the middle sessions, several of the group members got into a discussion about how they seemed to be a lot more competent at solving problems related to their handicapped child than they were with those involving other people. "That makes sense," said one of the parents, "we spend most of our time focusing on our kids. In fact, even when we go to parent association meetings all we ever seem to talk about is our kids. That's why this group is so important, here we're supposed to talk about us for a change."

One additional illustration of the change in orientation among most parents in the group occurred in our final meeting. During this session, one of the participants got into an emotional discussion of a conflict she was presently involved in with one of her relatives. When one of the other participants commented that she probably would not have the problem if it were not for her handicapped child, the women angrily retorted that this problem had nothing to do with her daughter. Other members in the group nodded their agreement.

Overall, the content and process of our training sessions confirmed a number of our initial hypotheses regarding the relevance of our approach. The parents in our group clearly had some very significant problems with managing conflicts with other individuals in their lives who could potentially offer much needed social support. The group also demonstrated, at least initially, their tendency as individuals to focus inordinate attention on the disabled child even to the point of blaming or attributing all the significant problems they had to their child. As the group member became gradually more aware of their own role in creating some of their problems, however, they came to appreciate how useful it was to have a training experience that focused attention on them for a change, instead of on their child.

Problem Solving Skills

The measure utilised to assess participants' problem-solving skills was the MEPS (Platt & Spivack, 1975) described earlier. Despite the small sample size which precluded statistical tests of many relationships, a number of interesting findings seemed to have emerged from the MEP's results and deserve discussion.

On the MEP's stories completed by participants prior to their training, the group used an average of 1.5 relevant means in each story, with 65% of these means being rated a relevant. When the three categories of problems presented to group members were considered individually, participants demonstrated markedly greater proficiency with the problem related to a handicapped child as compared with either interpersonal problems or intrapersonal problems. Specifically, prior to training, the ideas generated by group members for dealing with problems involving their child were twice as likely to be rated as effective and relevant as were those they generated for resolving problems involving themselves or others. Given the very small sample size, the significance of this finding should not be overstated. However, it is consistent with what the group members independently acknowledged about themselves and is certainly a finding worth testing in subsequent studies.

When the group members' scores on the MEPS stories completed after training were calculated, the results indicated definite improvement. The average number of relevant means they used in each story increased from 1.5 to 2.3, and the proportion of these that were judged relevant and effective also increased noticeably. Such improvement clearly parallels that found when a similar training program was utilised in an alcoholic treatment program (Intagliata, 1978). While no control group was utilised in this study to rule out the possibility that subjects improved performance was simply a result of repeating the MEPS testing, use of a control group in the comparable study demonstrated no significant change from pre-to-post testing.

When the post-training MEPS scores were considered separately for the three problem categories, results indicated greater improvement in the interpersonal and intrapersonal problem categories compared with that for the problems related to a handicapped child. The average number of relevant means included in stories dealing with interpersonal problems increased from 1.0 to 2.5 and the relevancy ratio (proportion of all means generated that were relevant and effective) increased from 54% to 100% for intrapersonal problems, the average number of relevant means per story increased from 1.0 to 2.2 with the relevancy ratio improving from 50% to 100%. Finally, for the problem related to a handicapped child, the average number of relevant means increased from 1.5 to 2.0 while the relevancy ratio remained at 100%. This suggest that the training may have had its effect where it was most needed.

Parent Follow-Up Reaction

Three months following completion of the training sessions, parents were contacted by letter and asked to complete a brief follow-up questionnaire evaluating the training. All participants felt that the sessions had been helpful for them. Particular ideas that participants felt had been most helpful included the importance of not making assumptions or jumping to conclusions when solving conflicts with others and the value of pushing yourself to bring a problem out into the open in order to discuss it with the other person. All participants also reported having consciously utilised the problem solving principles in dealing with problems they had encountered since training had ended. Further, all indicated they would recommend attending such a group to any parent who had a developmentally disabled child. Suggestions for improving the sessions included increasing the size of the group and perhaps running separate groups comprised exclusively of couples or single parents. While the results of most participant evaluations of service interventions tend to be overwhelmingly positive, these responses are nevertheless encouraging.

Discussion

The results of this pilot study indicate that a group designed to enhance the interpersonal problem-solving skills of parents with developmentally disabled children is a relevant and potentially helpful service intervention. While it was not an objective for this study, it will be important for subsequent research to assess the degree to which improved interpersonal problem solving competence actually facilitates the strengthening or broadening of parents' social support networks, insofar as it is this support that seems so essential to helping them cope with their significant stress.

It is hoped that the report of this study will lead those service providers involved with parents of the developmentally disabled to consider the need for interventions that focus on parents' needs, independent of their disabled child. The approach described here seems to be promising, but is only one such alternative. It is not our intention to suggest parent-focused interventions as a substitute for the many other services which help parents to better manage problems and caretaking burdens related specifically to their handicapped child. However, we do think that parent-focused interventions have been relatively neglected and should be considered an important component in any comprehensive package of supportive services made available to parents whose children are developmentally disabled or who suffer from other serious handicapping conditions.