ANNOTATED BIBLIOGRAPHY

Parents of Emotionally Handicapped Children:
Needs, Resources, and Relationships with Professionals

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INTRODUCTION

This annotated bibliography was developed from a literature search conducted over two broad topic areas: (1) relationships between professionals and parents of handicapped children, and (2) groups or organizations for and of such parents. Although the focus of the search was on literature pertaining to seriously emotionally handicapped children, other handicapping conditions were included for two reasons. First, there appear to be a number of common themes and issues for parents across types of handicap. Secondly, the literature specific to emotional handicap is sparse.

The bibliography is divided into seven sections which are by no means mutually exclusive, as the nature of the literature itself does not lend itself to such clarity. These broad categories do, however, reflect some major themes encountered in this review, and thus provide a kind of "road-map" through this material.

The first section, Parent-Professional Relationships, contains the literature specifically addressing how professionals and parents of handicapped children interact and communicate. This literature reflects very little research about how parents and professionals actually behave. The majority of the books and articles located focus on what should be, i.e., opinions and suggestions about how to improve the parent-professional relationship.

The parent-professional relationship is examined from a variety of perspectives. One clear view of the relationship between parents and professionals is written for professionals from the professionals' perspective. Much of this literature contains advice about managing parents' reactions and behaviors in relation to the educational or helping process. Much of this advice appears to assume that families are likely to be difficult, or resistive to involvement, hence need "management." The articles by Anderson (1977) and Braiman (1977) exemplify this perspective.

Another group of articles are also aimed at a professional audience, but attempt to interpret and explain the needs and reactions of families of handicapped children. Works such as those by Burggraf (1979) and DeLuca and Salerno (1984) assume this perspective and call for changes in professional attitudes and behaviors.

A number of authors provide commentary on the parent-professional relationship from the parents' point of view [e.g., Howe (1985), Mittler (1979), Terkelsen (1983), Turnbull & Turnbull (1978), and Sonnenschein (1981)]. Authors such as Feldman and Rosedal (1975) and Pepper and Ryglewicz (1984) report on programs designed to promote parent-professional collaboration.

The small amount of research on the parent-professional relationship that was located was largely designed to elicit family members' views of their encounters with professionals. Hallinan (1976) and Holden and Levine (1982) report on two of these research efforts.
The next two sections focus on parent groups. The first reviews some of the literature on Parent Groups and Programs Organized by Professionals, while the second contains examples from the literature pertaining to Parent Self-Help Groups. Although each section addresses groups and organizations of and for parents, differences in goals, respective roles of parents and professionals, and in some cases, results, appear to warrant separate treatment.

Similarly, the fourth and fifth sections both address parent participation in helping and educational processes, but are separated because the emphasis of each appears to be quite different from the other. The section, Parent Participation in the Helping/Educational Process, contains much general literature describing both what is and what should be. Many of the discussions revolve around issues raised by the requirements in P.L. 94-142 for parent involvement in the educational planning process. The bulk of these discussions are from the point of view of professionals. Much of the literature includes, at least implicitly, the expectation that parents and professionals should work together on behalf of handicapped children. The next sections, Parents as Aides, Helpers and Therapists, includes proposals or descriptions of programs that feature a specific set of roles for parents such as "teacher's aide," or "co-therapist." These approaches are designed to teach specific skills to parents and they often involve the parents' adopting a "learner" or "assistant" role in relation to the teacher or mental health professional. These programs also sometimes have the stated or unstated purpose of changing the parents' behavior in their children.

The section entitled Parents' Problems, Needs and Characteristics contains the largest number of articles based on research in this bibliography. This body of research examines the needs and characteristics of parents in relation to both their own handicapped children and the professionals and services that comprise the system of care for these children and their families.

The last section, Guidelines and Programs for Parents and Professionals, contains selected literature that is designed to increase skills or provide practical "how to" information, and that describes training approaches or programs for parents and/or professionals. This section also includes other written guides, handbooks and resource materials.

In compiling this bibliography we made a special effort to locate and include relevant research literature, and such material is designed by an asterisk (*) preceding the reference. There has been much more study of parents' characteristics and needs than of either the nature of the parent-professional relationship or the characteristics of effective programs involving or responding to the needs of parents. There is also very little research examining the problems and responses of professionals to working with seriously handicapped children and their families. The research that exists should be of interest to parents and professionals alike. The research that has not yet been done points to an agenda for the future.
Paren t-Professional Relationships


Techniques for involving the families of hospitalized psychiatric patients in treatment are suggested. The author urges the establishment of a collaborative relationship between the hospital staff and families by combining the systems and medical models. Although the significance of family variables should be acknowledged, the patient's mental illness should be accepted as the focus of treatment. Eight techniques for involving resistant families in treatment are recommended. Suggested techniques include immediately contacting the family at the time of the patient's hospitalization, appointing a family representative and making the staff available to the family for phone calls and meetings on scheduled evenings and weekends.


The diagnostic and therapeutic "shopping" of parents of retarded children is described as a learned response to unsatisfactory contacts with professional people regarding their child. The role of the professional person in initiating or preventing, and stopping shopping behavior is discussed, with special emphasis on the informing interview. The need for research in this area is underscored, and areas for research are suggested. (Author's abstract)


Twenty-three mothers of retarded children were interviewed individually concerning their experiences with professional people in regard to their retarded children -- from the time the child was born until the time of the interview. The kinds of professional people the mothers visited, the types of visits that were made and the mothers' satisfaction with these visits are described. Results indicated that specific professions and visits made for diagnoses generate a low degree of maternal satisfaction. Professional people who are consulted by parents of retarded children are cautioned to consider the role they may play in contributing to the "shopping" behavior so often noticed in these parents.
Parent-Professional Relationships


The author recommends changes in the behavior of professionals toward families which will improve both the family's and patient's treatment. Mistreatment of families may take the form of simply ignoring them, expressing hostility toward them or making vague innuendoes about them. Mistreated families may retaliate by becoming less willing to tolerate the patient's problems, less willing to change their treatment of the patient, reluctant to share knowledge with professionals, and unwilling to regularly visit the patient. Professionals should present themselves in a nonthreatening manner, obtain the family's support and create an alliance with the family. Professionals must recognize that their treatment of a family sets an example for staff to follow. Families should be respected, treated with understanding and sympathy, and viewed as a pool of fund raisers, teachers and volunteers.


The article introduces a special issue on social networks. In addition, the author argues that a coalition between researchers, service providers and mental health consumers and their families is politically inevitable. The author envisions that such a coalition or treatment team would take the following form: "A hospital or community mental health center would have an evaluation clinic-emergency room where, after a sophisticated work-up, patients and their families would be referred to treatment programs tailored to the individuality of their biological and social requirements, and would at the same time become members of a self-help consumer organization." The self-help consumer organization would, among other services, offer its members information on schizophrenia, supportive family discussion groups and social programs for schizophrenic relatives.


Supportive family counseling for families of schizophrenics is designed to provide emotional support, information and recognition of the needs of individual family members. Such counseling is distinguishable from family therapy as there is no goal of reorganizing the structure of the family. Supportive family counseling assumes only that schizophrenia is a chronic condition. Its goal is to encourage the family's continuing caretaking involvement with the schizophrenic family member. Supportive family counselors: (1) provide information regarding the illness; (2) explore treatment options with the family; (3) help family members develop realistic expectations; and (4) assist the family in developing monitoring skills. The counselor further helps the family resolve daily living problems. Difficulties experienced by supportive family counselors are also explored.
Parent-Professional Relationships


The preconditions for a successful therapeutic alliance between professionals and the parents of psychiatrically hospitalized children are examined. Initial parental resistance to treatment at the time of the child's hospitalization may arise from any of the following four factors: (1) parents may feel they are to blame for their child's condition and may disrupt treatment in a search for a physical cause or magical cure; (2) parents may experience anxiety over their child's separation from them, and may, in response to the fear that their child may never come home, promptly attempt to remove their child from the hospital; (3) upon recognizing that family conflict may not be resolved simply by hospitalizing one of the family members, the remainder of the family may actively resist efforts at family intervention; and (4) the family may experience a new disorganization because its members are deprived of all caretaking functions for the disabled family member.

Social workers should: (1) discuss plans with the family at the time of the child's hospitalization; (2) advise parents of their rights as legal guardians; (3) advise parents that subtle deviations from normal developmental patterns can have profound consequences; (4) help parents feel needed by garnering information from them about their child's needs and habits; and (5) help other hospital staff members understand the sense of abandonment parents feel when their child is hospitalized.


Counselors can play an important role in assisting parents of disabled children to develop the strength to accept the special challenges they experience. Counselors can assist parents by providing accurate and timely information about their child's condition, recognition for the work they have done, progress reports and information regarding their legal rights. The author offers suggested counseling guidelines and a list of characteristics parents of disabled children have indicated they desire.


A literature review examined the extent to which mothers are blamed for whatever goes wrong with their offspring. It attempted to determine whether reductions in the blaming of mothers have resulted from the efforts of the women's movement. Data were gathered by means of an evaluation of 125 articles that were published in nine journals in 1970, 1976 and 1982. On the basis of approximately 50 clinical articles from nontarget years, 63 items that fell into five categories were used to evaluate articles from the target years. Findings revealed few changes across the target years and the blaming of mothers was only slightly affected by the type of journal and by the sex of the author. The study concluded that the blaming of mothers is a significant and serious problem that continues to exist in the current literature. (Journal abstract, edited)
Parent-Professional Relationships


This article focuses on ways in which helping agents, including family therapists, become part of the problem they are treating. Particular emphasis is placed on triangular patterns that frequently develop when one agency involves another in carrying out its functions and in diffusing conflict with a client and his or her family. We refer to this process as an agency triangle. Case examples of such triangles involving various service systems (e.g. schools, courts, mental health centers) are presented, followed by a discussion of how agency triangles can be prevented. (Journal abstract)


The Parent/Family Involvement Index (PFII) is an objective, 63-item test which measures twelve types of parent participation in a special education program. It is based on the idea that how parents are involved with their children's education and to what degree, is important as opposed to simply whether they are involved or not. The results showed that mothers were significantly more involved than fathers in nine areas. There was a positive correlation with parent involvement and family income and parent education levels. There was a negative correlation with the child's grade level and the mothers' involvement, although that was not the case with fathers.


The author states that the nature of aftercare programs for multiply disadvantaged patients and chronic schizophrenics requires that psychiatrists learn to work collaboratively with professionals in other disciplines. Psychiatrists must attend not only to the medication patients require but must also coordinate the comprehensive medical therapies, socialization activities, and occupational and pre-vocational therapies. Psychiatrists must also regularly and frequently make themselves available for consultation with both patients and staff. The future prospects of psychiatry may be determined by psychiatrists' willingness to assume collaborative, coordinating and consulting roles.

The book's intended audience is professionals working with young disabled children. The authors regard professional collaborative efforts with the families of the disabled as vital. Families' response to the presence of a disabled child in the family and the manner in which professionals interact with the families of the handicapped are examined through an exploration of numerous factors, including family and professional coping mechanisms, family and professional support groups, family and professional home life, socioeconomic conditions and cultural background. Types of family members (super family member, angry, anxious, depressed, bizarre) and types of professionals (the super professional, anxious, angry, professional professional and depressed professional) are presented in a number of scenarios followed by materials for consideration and discussion. The authors urge: (1) the development of efficient communication skills; (2) the formation of support groups for, respectively, professionals and families; and (3) the development of an understanding of the interplay of coping mechanisms, interactive style, support network, cultural values, socioeconomic conditions, perceptions and family as they impact upon professionals and the families with whom they work.


Approaches to treatment of young physically handicapped children are often convenient from the professional's point of view, but may have deleterious effects on the family. Case histories are presented where family members are shown to be suffering not only from the handicap of a child but from insensitive treatment by professionals who focus on their own specialties and disregard other perspectives and considerations. Suggestions are made for improving services to include cooperation with the whole family in treatment planning and better accommodation to parents' schedules when making appointments.


This is an introduction to a symposium on parent-professional relationships in dealing with the mentally retarded. The author emphasizes the complexity of relationships as: (1) staff need to be sensitive to parental grief and acceptance processes, and allow parents to maintain the primary role as parents; and (2) once the chronological end of childhood is reached, parents need to release more responsibility for their offspring to staff.
Parent-Professional Relationships


A parent involvement program at a center which serves multiply handicapped children is described. The parent involvement program was designed to carry the program's work into the home and create a sense of community. The program emphasized behavioral change and, when appropriate, parents were encouraged to employ specific techniques at home with their child. Parents responded favorably to the suggested use of a home behavioral program, shared their concerns about their child and displayed a new appreciation for their child's strengths.


The authors suggest that parents of the mentally handicapped tend to demonstrate greater satisfaction with the professionals who provide educational, psychological or medical services to their children than they did in the past. The change in parental attitudes may be a reflection of the broad-based changes in society's attitudes towards the mentally ill and their families.


The author asserts that the most critical variable in the provision of quality services to the handicapped and their families is the level of communication between clients, their families and professionals. Five suggestions designed to help facilitate communication are offered. They include assuming the other individual acts in good faith, agreeing on specific goals and developing a feedback system. The author identifies education, emotional support, identification of realistic alternatives and the provision of ongoing services as the four most critical needs of the disabled and their families.


The author, the parent of a profoundly retarded child, offers eight suggestions to professionals and nine suggestions to parents which are intended to improve communication between parents and professionals. Suggestions for professionals include encouraging parent involvement at every phase, writing reports in understandable language and insuring that parents understand their children's abilities as well as their disabilities. Recommendations for parents include learning to keep records, encouraging professionals to employ lay language and insisting that they be treated as their child's primary coordinator and decision maker.
Parent-Professional Relationships


Ninety-four families were surveyed with respect to the birth of their disabled child and their relations with the medical and nursing professions. Parents want to be promptly informed regarding their child's handicap and recommend that both parents be present at the initial interview. They would like to be provided with literature about their child's condition and the freedom to return for additional appointments when further help is needed. Parents also want appropriate referrals to other professionals and to similarly situated parents. Upon first learning of their child's disability, parents are initially concerned about: (1) their child's future; (2) their ability to cope; (3) the child's well-being; and (4) the cause of the handicapping condition. At this early stage, parents express little interest in personal counseling for themselves or in financial assistance.


The "world views" of families of the mentally ill and mental health professionals are reviewed. The emotional burden of families and their needs in therapy are described. Five views of families containing a mentally ill member are summarized: (1) hierarchical incongruity; (2) disordered communication; (3) emotionally disturbed families; (4) high expressed emotion and (5) severely strained adaptive capacities. The more congruent a therapist's view is with the family's, the more likely it is that each will experience satisfaction and each will behave cooperatively.


The author points out the distances between mental health professionals and the families of the mentally ill and urges the building of bridges between them. Mental health professionals learn about mental illness in a professional setting and view families as either the cause or a contributing cause of the mental illness. Families learn about mental illness as a major catastrophe which causes enormous family grief. The development of an alliance between parents and professionals is critical in order to insure quality community care.
Parent-Professional Relationships


A mail survey solicited evaluations of mental health professionals by families of chronically mentally ill individuals. Families expressed great dissatisfaction. The predominantly white, female, educated survey respondents reported: (1) dissatisfaction with the level and type of involvement they had with professionals; (2) dissatisfaction with the help they were provided (inadequate information about the illness, abandonment by professionals during the mentally ill individual’s community resocialization, and inadequate assistance in locating community resources); and 3) a profound effect of the mental illness upon the family (stressful family relationships, social isolation, health problems, etc.).


The author encourages child caregivers to enlist the participation of parents in the education of their handicapped child. The different views and perspectives of the providers and the parents are explored. Providers need sensitivity and understanding of the parents’ guilt, anger, and self-blame. The attitudes the caregivers hold often hinder a trust relationship from forming. The author suggests thirteen ways by which providers can improve the parent-professional relationship. Included among the suggestions are praising the accomplishments of the parent and child, initiating the relationship with parents as early as possible, providing information about child development and acknowledging that parents are experts with respect to the experience their children have had.


Pediatric subspecialists in handicapped children serve a variety of roles with families and disabled children. During the initial diagnostic phase their roles include helping parents sort through consultations and test results, assisting the family's efforts to adjust to the disability and assessing the child's behavioral and physical strengths and deficiencies. Subsequently, their role may include recommending an early intervention program and linking the family with community resources. Pediatricians should attempt to build a partnership with parents by acknowledging parental concerns, helping them develop realistic expectations for the child's development and encouraging parents to balance the disabled child's needs with those of other family members.

Families of the mentally ill believe that they ought not to be the primary caregiver of the disabled family member for three reasons: (1) parents and siblings are on duty 24 hours a day and experience enormous tensions; (2) the family does not provide the best environment for developing independence; and (3) parents generally die before their children, and their disabled family member is likely to be hospitalized or homeless if he or she has lived at home and failed to develop independent living skills. The author believes that families should be viewed as important participants in their disabled member's rehabilitation who should occupy roles other than primary caregiver and housing provider.


That portion of a British survey which examined services to disabled children and their parents and which addressed the quality of information provided to parents is reported. Parents need information about: (1) available services and benefits; and (2) their child's diagnosis and prognosis. Parents expressed dissatisfaction with their communications with professionals and viewed other parents as a major source of information about available services. Because physicians seemed disinterested, they relied on other families to provide adequate explanations of the children's handicaps. The surveyors made three recommendations designed to improve working relationships. Physicians rejected the recommendations claiming: (1) they do provide full information to families; (2) parents are often resistant to learning the truth about their child's condition; and (3) parents often remain dissatisfied under any circumstances. Given that learning of one's child's handicap is emotionally loaded information, professionals must learn to regularly repeat the information until it is actually absorbed. Moreover, the belief that parents do not want to know the truth and remain dissatisfied under any circumstances is professional mythology which absolves the professional of responsibility to the family.


Educating handicapped children about sex is often an anxious and conflict ridden process for parents and teachers. Much sex education happens gradually and non-verbally in the attitudes and experiences encountered by the child in the home and community. The teacher's responsibility is to supplement and round out the child's understanding. When parents and teacher collaborate by working out mutual expectations, goals and limits, the exceptional child can be greatly aided in integrating sexuality as a positive part of his/her self.
Parent-Professional Relationships


Self-help groups are growing more acceptable to professionals. Complementary collaboration between lay volunteers and professionals is emerging. The authors distinguish between autonomous self-help groups and the use of self-help principles and methods in lay-professional collaboration. This article explores some of the basic dilemmas of employing self-help principles in a partnership between professionals and volunteers.


The editorial asserts that professionals spend endless hours completing complicated forms and repeatedly assessing children for the purpose of insuring that Public Law 94-142 is properly being implemented. Money and time are diverted from providing direct services to children in order to perform these other functions. Such procedures must be modified when they intrude upon the relations between parents and professionals and upon the provision of services to children. Parents and professionals must monitor programs to insure that they serve the unique needs of each child.


The first of a two part series on social workers describes the history of the social work profession and the training prospective social workers must receive. The three traditional fields of social work practice (social casework, social group work and community organization) are explained.


The second of two articles on the social work profession describes the services social workers provide to disabled children and their families. Family agencies, hospitals, schools, community mental health and residential treatment centers are discussed.


This first of a three part series designed to introduce parents to the educational training and professional duties of psychologists focuses on explaining the training received by psychologists and discusses the duties of the three types of psychologists with whom the parents of disabled children are most likely to interact: clinical, school, and counseling psychologists.

The second of a three part series on psychologists introduces parents to the psychological assessment process and particularly emphasizes psychological testing. Advice is offered with respect to how to prepare children for psychological testing. Intelligence and personality tests are also discussed.


The third of a three part series on psychologists introduces parents to the role psychologists play in assessing children by interviewing and observing children and their families. Advice is offered with respect to how to prepare children for assessment interviews. Explanations of group and individual therapy processes for children are discussed.


When a child cannot meet the developmental tasks for his/her age, and no physical problem is found to exist, parents are encouraged to seek the assistance of mental health professionals who can educate, consult and work directly with the child. The differences and similarities in training and functions of psychiatrists, psychologists and social workers are delineated.


This editorial emphasizes the importance of communication between parents, teachers and administrators and suggests greater effectiveness could be achieved if participants appreciated each other's perspectives. Parents are cautioned to remember that teachers may not be trained in conference skills, and teachers are reminded parents may attend conference sessions with negative expectations as a consequence of previous poor parent-teacher conference experiences.


The parents of the handicapped often have low self-esteem and self-confidence as a result of painful experiences in their efforts to rear their disabled children. These feelings may be reinforced by professionals who emphasize areas in which parents have not felt successful and who don't focus on areas in which parents feel capable. Successful collaborative efforts between parents and professionals require: (1) an examination of families' experiences with their disabled child; (2) increased understanding of their children's abilities and an understanding of the programs and experiences which can right developmental problems; and (3) increased knowledge of how parents and professionals, respectively, can work to improve the lives of disabled children.

This module (part of a series of 24 modules) is on philosophies, competencies, and skills that will aid the teacher in communicating with parents. The genesis of these materials is in the 10 "clusters of capabilities," outlined in the paper, "A Common Body of Practice for Teachers: The Challenge of Public Law 94-142 to Teacher Education." These clusters form the proposed core of professional knowledge needed by teachers in the future. The module is to be used by teacher educators to reexamine and enhance their current practice in preparing classroom teachers to work competently and comfortably with children who have a wide range of individual needs. The module includes objectives, scales for assessing the degree to which the identified knowledge and practices are prevalent in an existing teacher education program, and self-assessment test items. Topics discussed in this module include a rationale for parent-teacher interaction, a mirror model of parental involvement, listening skills, conferencing skills, information-sharing strategies, and parent involvement groups. A bibliography and articles are included on parental involvement with the schools, and improving conferences with parents of exceptional children. (ERIC Abstract).


In a commentary, the author argues that mental health professionals have added to the guilt families of the mentally ill bear by, for instance, labeling a schizophrenic's mother a "schizophrenogenic mother" and by suggesting that schizophrenia results from parental problems and parent-child interactions. As a consequence of the parents' self-help movement professionals are learning to offer families support and empathy and are developing alliances with families for the purpose of rehabilitating and managing the mentally ill.


Professionals working with the parents of culturally diverse exceptional children are urged to appreciate their cultural differences. Citing an earlier study, the author states that the families of minority handicapped children are more inclined to feel protective and accepting of their disabled child than to feel the shock, disbelief, and grief many Anglo-American families demonstrate towards their handicapped children. Parents of culturally diverse handicapped children do, however, display dismay and anger at the fact that a higher proportion of minority children are referred to special education programs for the emotionally disturbed and mentally retarded. Culturally diverse parents of handicapped and gifted children need: (1) information; (2) to feel that they belong; and (3) to have their self-esteem enhanced. Improved communication between parents of culturally diverse children and professionals will serve their common interest in meeting the needs of children.
Parent-Professional Relationships


The authors propose that the relationship between educators and parents be redefined. Parents and educators must mutually share a sense of responsibility for the educational performance of their children. A model is presented which suggests that individualized educational agreements should identify and set forth a number of specific parental obligations and duties which will enhance the likelihood of educational success. A system for updating agreements and monitoring their performance would assure that the goal of insuring that both parents and educators would be mutually contractually bound to seek children's fullest academic potential would be achieved.


The first article in a two part series discusses the roles played by community nurses and the services community nurses offer to disabled children and their families. Community nurses are those such as public health nurses, visiting nurses, and school nurses who provide services outside the hospital setting. Community nurses offer supportive family counseling, physical care and teaching to families with disabled children. Services are designed to encourage family self-sufficiency. Suggestions are offered to parents of school age children with respect to the information they should provide to school nurses to enable the nurse to serve as a connecting link between community facilities, the family and the school.


The second article in a two-part series discusses the various types of hospital nurses. The four organizational patterns of nursing care delivery (case nursing, functional nursing, team nursing and primary nursing) are explained and parents are advised with respect to the channels to pursue to express concerns regarding the nursing care their child is receiving within each type of delivery system.
Parent-Professional Relationships


Partnerships between parents and professionals must be formulated on the basis of equality. Each party contributes skill and knowledge in their efforts to serve handicapped children. Partnership requires parents and professionals to jointly assess and make decisions about handicapped children. Professionals must recognize that the parents of the handicapped represent all segments of society and have only a handicapped child in common. Professionals must allow parents to choose not to extensively collaborate with professionals if they so desire. Some parents may be reluctant to participate in the collaborative partnership as some professionals make it a one way partnership. "[S]ome professionals have been so busy teaching parents to be teachers, psychologists and psychiatrists, not to mention research workers, physiotherapists and speech therapists that there may not be enough time for parents to be parents." Residential care workers exemplify the blurred roles between those of parents and professionals. Their task is to attend to the emotional and social needs of the children in their care. They must become as skilled as parents in working in partnership with other professionals, schools and development centers to insure the maximum development of the children in their care.


Four mothers of young disabled children who belonged to a parents' group and three professionals participated in a panel discussion. This excerpt of their discussion emphasizes that parents want professionals to provide them with information regarding their child's condition, teach them that their mourning reactions and difficulty in coping are normal responses to their child's condition, inform parents of available resources and introduce parents to others similarly situated. Moreover, professionals should maintain their objectivity, but simultaneously acknowledge their emotional response to the disabled children they serve.


The authors present a model which stresses commonalities between parents of children with cleft palate and related deformities and professionals. Both share the common goals of encouraging education, research and rehabilitation. Both share the duty to communicate with the other and provide information. Both strive for competency and both require education about cleft palate rehabilitation. Lastly, each participates in parent or professional group organizations offering support and education. Eleven suggestions for action include the publication of a newsletter designed to bridge parents and professionals, professional awareness of financial assistance available to families and the publication of a directory describing available financial resources, the maintenance of a free national telephone hot line offering the most current information and nationwide traveling resource teams that would offer workshops.
Parent-Professional Relationships


This book addresses the needs for cooperation between parents and teachers of young moderately and severely handicapped children. Chapters written by various professionals provide suggestions and helpful information on subjects including family dynamics, the law, ethical issues in cooperating with professionals, the educational system and public social policy. A final vision of possibilities for special education in the future is provided.


Specific guidelines designed to improve relations between families and professionals are offered. The nine guidelines for clinicians include suggestions that they openly share information with families, meet regularly with families during a crisis or hospitalization, offer educational opportunities to families and encourage family involvement in support groups. The five guidelines for parents include recommending that parents view mental health professionals as individuals and encouraging their cooperation with treatment plans. The seven recommendations for agencies include suggestions that they establish family crisis groups and develop programs designed to improve family caregiving, stress management and communication skills. These suggestions were generated in joint meetings of professionals and family members.


A simple and easy-to-use report card system, based on a handicapped child's individual education plan (IEP), was designed and implemented by the parent who wrote this article. The author underlines the importance of two-way communication between home and school, describes some methods that did not work and testifies to the effectiveness and success of this method. Clear illustrations of sample cards are included.


The authors urge an active collaboration between the families of the mentally ill and mental health professionals which they believe will result in more effective treatment of disabled family members. The authors' intended audience includes professionals, family members and friends of the mentally ill. The varieties of mental illness within the family unit (including denial, guilt, acceptance, etc.) and the impact upon the family of various types of psychiatric treatment are described.
Parent-Professional Relationships


The author suggests that while it may be unclear whether people receiving help are usually benefited, it is probable that the individuals offering help are benefiting. The so-called "helper principle" may be described as "self-persuasion through persuading others." Social work should attempt to create a role reversal and turn recipients of help into dispensers of help. The helper principle encourages an improved self-image and the development of leadership. The helper principle may be employed with students, in correctional institutions and with both inpatient and outpatient hospital groups.


Teachers are the intended audience of this text. Specific techniques are suggested to cooperatively involve parents in their children's education. Special attention is paid to the parents of handicapped children. Public law 94-142 is explained and methods of informing parents of their handicapped child's school progress as well as the role teachers play in informing parents of their child's handicap are discussed. Suggested techniques for parents and teachers to serve as child advocates are described. A very detailed teacher-parent advocacy team approach designed to maximize children's daily learning experiences and their daily interpersonal interactions is presented.


The needs of families, patients and therapists are delineated. Families need the following: help in crises, information, contact, advice, an understanding of the problem facing the family and an understanding of what the future holds. Patients need alternative living situations which enable them to live outside the family home or assistance in learning new ways of interacting and handling conflict and tension. Therapists need to assess how the family as a whole and each individual family member is coping with the mental health problems of one of its members. Therapists need families to conduct themselves in a manner which is in the best interests of the patient. Therapists and treatment agencies may meet the needs of families, patients and professionals by providing: (1) extensive services and maximum contact during the crisis period; (2) continuing follow-up after the crisis; (3) indefinite continuing availability; and (4) the availability of more intensive therapy.
Most people favor parent-professional collaboration in the treatment of handicapped children, but conflicts and difficulties have arisen in attempting to translate this concept into practice. Explanations for these barriers have primarily focused on the psychological attributes of the individuals involved. Here it is suggested that these difficulties are inherent in the power imbalances of the parent-professional relationships that limit parent participation. Ways to reduce the power differential are discussed. In general, parent coalitions and advocacy groups are suggested as most effective.


Parents' attitudes towards teachers as well as teachers' attitudes towards parents are examined. Patterns of parental reaction to the presence of a handicapped child in the family are discussed. Interviewing principles, strategies for working with parents of the handicapped and tips for working with difficult or disturbed parents are explored. Nineteen parent teacher conference situations are presented which may be used for discussion or role playing purposes. An appendix offers information on social service agencies, self-help organizations, and literature of interest to the parents and teachers of the handicapped.


Five sequential stages for family assessment and treatment are described. A gradual understanding and commitment from the family unit is developed for the formation of a therapeutic alliance, which can handle the family's self-exposure to the therapist. When family treatment is staged in sequential steps, the therapist can focus interventions with the family. The author argues that insight is not always necessary for change to occur; therefore, this model allows for the sustenance of changes while skipping one stage.


The uneasy relationship which exists between parents and professionals results from, among others, the following attitudes: (1) the parent is perceived as a vulnerable client; (2) professionals choose to maintain "professional distance" from their clients and fail to display normal feelings; (3) parents are viewed as troubled patients rather than as parents with strengths; (4) parents are blamed for their child's condition; (5) parents are viewed as less observant, intelligent and perceptive; and (6) parents and professionals view each other as adversaries.

Families complain that professionals often fail to provide a clear diagnosis, information about the illness, information on management techniques, supervision of medication or living arrangements and further display a lack of familiarity with community resources. Families find therapy unsatisfactory as they desire practical information and advice. Therapists focus upon family dynamics and seemingly find families culpable for the mental illness. Fifteen suggestions designed to help professionals learn to share power with the families of the mentally disabled are offered. The suggestions include working collaboratively with the family and other resources as a treatment team, acknowledging that families do not conform to specific models, and learning to provide information on daily management skills.


The commentary urges mental health professionals to set aside the medical model. Families of the chronically mentally ill wish that professionals would have reasonable expectations and understand that imperfectability is a condition which must be accepted. The concept of imperfectability may benefit chronic patients by encouraging long term relationships with professionals. "Professionals would benefit by their emancipation from the burden of 'curing' and their new freedom to pursue the more reasonable and humane roles of teacher, advocate, and friend."


The importance of establishing an alliance between the families of recently institutionalized psychiatric patients and the institution is stressed. Treatment plans which include the family, address the importance of the family's role in the patient's rehabilitation, and form an alliance between the treatment team and the family are central for an effective outcome. At the early stage of hospitalization and treatment, families need emotional support, acceptance by the staff, information about the patient's condition and prognosis, an understanding of the facility's program and an understanding of the roles and authority within the institution. The institution needs the family to: (1) give it the authority it needs to perform its duties; (2) give a social history and participate in procedures designed to evaluate the family; and (3) display a willingness to be open to the institution's programs and efforts to help the family member. A four stage model (crisis, separation, reinvovlement, assessment) for building a family-institution alliance is described.
Parent-Professional Relationships


Parents complain that communication problems between professionals and parents include professionals' failure to provide parents with sufficiently detailed information and explanations, failure to provide practical management techniques, and a failure to actively listen to parents. Parents often fail to meet their responsibilities to their children. Even though aware of their child's problem, some parents fail to act and expect professionals to notice the difficulty and take appropriate action. When a diagnosis is confirmed by more than one team of diagnosticians, parents should accept the diagnosis at least for purposes of taking corrective measures. Parents should actively participate in parent organizations and not leave the duty to work for improved services to other parents. Suggestions are offered for testing and meeting with the parents of learning disabled children.


The author reflects on his work with families of seriously disturbed patients and argues that when either the therapist or the family believe that schizophrenia is caused by interaction with other family members "therapeutic malaliance" will likely follow. Such a belief constitutes a barrier to trustful collaboration between relatives and the therapist. When the therapist conveys to the family his/her belief that the family is the cause of the problem, the patient and the family may avoid professional help and make long term adjustments to the schizophrenia. Professionals can communicate their belief that the family is to blame by concentrating his/her questioning on family life prior to the illness, by failing to acknowledge the effect of the illness upon the family and by not interpreting the disturbance in psycho-biological terms. Consequently, family members may feel guilty or their self-esteem may diminish. They may then reduce their amount of self-disclosure, devalue the family's usual methods of problem resolution, experience an increased sense of being encumbered by their ill family member and display an unwillingness to collaborate with the therapist.


England's 1981 Education Act, which addresses the provision of special education services to handicapped children, and which is known by some as the Parents' Charter, is summarized and critiqued in a one paragraph note.
Parent-Professional Relationships


The book's intended audience is professionals and parents who believe that professionals fail to view their problems from the parents' vantage point. The presence of a disabled individual in the families of professionals is explored. Fourteen parent-professionals contributed to the book. Of particular interest are discussions of professional ignorance of mental retardation, the myth of professional omniscience and omnipotence, self-fulfilling professional feelings of hopelessness about mental retardation as an incurable disability, suggested supportive services families require and suggested topics professional training programs should address.


Various aspects of parent-professional interactions are detailed, from a review of historical dysfunctions to a thorough study of the six principles of P.L. 94-142 and the regulations that delineate parental participation (zero reject, nondiscriminatory assessment, individualized education programs, least restrictive alternative, procedural due process and parent participation.) Ways in which parents and professionals can work together to develop parental roles of parents, teachers and advocates are suggested. Good communication and respect makes all the difference for effective parent-professional relationships in the complicated task of educating handicapped children.


This article is part of a symposium on parent-professional relationships in the care of the mentally retarded. The relationships are viewed in terms of parental responsibility and professional's need to give some care to the parents. A study of a 24-hour care institution in The Netherlands is described, and forms of parental-professional participation are evaluated.


Three factors affecting communication between parents and professionals are (1) physicians' education and familiarity with disabled children; (2) physicians' positive or negative attitudes towards handicapped children; and (3) physicians' skillfulness in communicating with parents. Pediatricians generally receive little formal training regarding disabling conditions and due to the misinformation about handicapped children many physicians have developed negative attitudes towards them. Doctors should be systematically taught communications skills through such techniques as role playing and videotaping. They should translate professional language into lay language when talking to non-doctors and should actively attempt to establish a dialogue with families to insure that the information they are attempting to convey is actually received and understood.
Parent-Professional Relationships


The author analyzes 133 literature references on disabilities and families. The book is divided into three major theme areas: (1) parental behavior and child development; (2) effect of disabilities on family life, and (3) helping parents. Particular attention is paid to the added handicap imposed upon parents by professionals. If professionals present information regarding a child's disability thoughtlessly or withhold the information, parents suffer a diminishment of their self-image. The development of parent self-help groups and various family therapies is delineated. The range of roles professionals may assume and the needs of families are set forth.
Parent Groups, Programs Organized by Professionals


The article describes a program which is designed to provide support and information to the families of schizophrenics so that they may serve as resources for the long term management of the mentally ill family member. The phases are: (1) connection - during which the clinician establishes a relationship and treatment contract with the family before any actions are taken; (2) survival skills - a daylong education workshop with other families early in treatment; (3) providing information on medications, management and self-maintenance skills; (4) re-entry- during which family sessions are held with the patient, emphasizing boundaries and patient responsibility; and lastly, (5) continued treatment or disengagement.


Parents have, by far, the greatest influence over children's development. Professionals can indirectly aid children by providing guidance for parents in the form of support, counseling, education and therapy. Practical suggestions for parent guidance are offered to professionals. The book addresses such topics as: methods of parent guidance, parents' groups or organizations, counseling the parents of learning disabled or mentally retarded youth, assisting parents of physically disabled or chronically ill children, collaborating with parents of autistic children, methods teachers may employ to establish an active alliance with parents, and suggestions for clergy seeking to help parents help their offspring.


The author reports the outcome of a workshop held for parents of 25 pre-school handicapped children. Parents particularly appreciated the multidisciplinary approach of team teaching, and were encouraged and inspired to try new alternatives in tutor groups. Parents learned about other parents' problems and approaches. Tutors emphasized the health of the whole family, rather than focusing on the handicapped child. After the workshop was completed, parents formed several self-help groups among themselves.
Parent Groups, Programs Organized by Professionals


The authors discuss a short term professionally led supportive group counseling model employed at a rehabilitation agency with the relatives of mentally ill adult clients. Initially, family members vented their disappointment, resentment and frustrations. They expressed anger at treatment failures and feelings of guilt about suggestions that they were responsible for their family member's illness. A group norm evolved which encouraged parents to emotionally distance themselves from their adult children and which further encouraged adult children to function more autonomously. Group members received permission to acknowledge their needs, enjoy a social life, obtain public financial support, and make full use of all available mental health resources. Members of relatives' groups demonstrate positive attitudes toward the agency's treatment program, a willingness to request extra help from the treatment staff and a willingness to encourage family members' use of other mental health services.


The St. Louis Association for Retarded Children initiated the Parent Outreach Program. The program links parents of disabled children with new parents of handicapped infants. The outreach program is professionally coordinated by the Association. Affiliation with the agency provides the program with a professional staff to train and consult with parent volunteers, a central referral office and potential funding sources. Parent intervention is intended to be short term. The parent to parent relationship includes providing information about the child's disability, helping new parents acknowledge and accept their feelings, locating community resources and providing information home training.


The normalization and deinstitutionalization movements have done much to shift focus for care of handicapped children from institutional to community-based care. Many legislative acts of the 1970's mandated both specific rights of the handicapped and community services. As a result, many developmentally disabled children are remaining at home. In order to offer parents a temporary break, families have developed, pushed and lobbied for respite care. Many models of care and in and out of home services and providers are described.
Parent Groups, Programs Organized by Professionals


Thresholds, a psychiatric rehabilitation agency, created a parents' group which is designed as a medium for encouraging adult children to separate from parents' homes. Four approaches are employed which promote the patients' independence: (1) good parenting stresses the child's independence; (2) parents must examine how they are preparing the child to live without them following their deaths; (3) the agency offers parents the tools to assist the family in achieving their child's independence and, if they do not seize the opportunity now, when will they?; and (4) encouraging the parents and child to acknowledge that there is little chance for the patient to improve within the family home.


As part of a symposium on parent-professional relationships in the care of the mentally retarded, this article describes a group for parents formed by a social worker who was also a teacher and staff advisor. Parents' issues and problems with the training school are described, as well as the direct positive effects of this group on improving relationships with teachers and staff.


In response to parents' demands for out-of-home, non-hospital care for their handicapped children, a short-stay home was created in Sweden. It serves three functions: short daytime stays, relief for weekend, and holiday and emergency care. The physical arrangements, staffing, daily routines, costs and philosophy of the program are described. Overall, the program is evaluated as successful. The home is intended to be as much like the child's home as possible, and teachers follow parents' guidelines on diets and discipline.


This article describes the formation and activities of a respite care co-op program formed in 1977 to give parents & handicapped children a break from each other by trading care with other families. Practical and emotional issues around operation of the co-op are described. The success of this program is ascribed to the fact that there was parent-professional cooperation in all phases.
Parent Groups, Programs Organized by Professionals


Tacoma, Washington's five agency Youth Services System is described. Parent participation is required in the McIlvaigh Project which serves 30 high risk adolescents. A monthly newsletter describing activities and weekly student reports are regularly sent to parents. Approximately twelve times a year project staff members visit parents in their homes to discuss their children. A parents' group is offered which provides families with an opportunity to talk about themselves and their children. The project sponsors an annual family dinner. Frequent staff initiated contact with families through home visits and telephone calls encourages parents who might otherwise be intimidated by the school to work with the program staff.


Parents resistive to family therapy were invited to join a group for relatives of schizophrenics as a way to engage them in treatment. Members were chosen for this group who were overly controlling, highly critical, or otherwise intrusive or uncooperative. The author describes the group's evolution from gripe session to a forum for peer support aimed at increasing the distance between parent and child. Parents who were unable to critically observe their own behavior were offered up to four pre-sessions with both group leaders to lend support and "hook" them into the group. This preparation reduced the risk of losing new members and fostered a positive alliance with the leaders. The characteristics of parents who do and do not profit from a relatives' group are described.


One hundred-twenty-two families participated in a pilot program for handicapped children and their parents designed to provide mutual support, information and enhanced communications among parents of disabled children. The program included weekly group sessions and recreation for the disabled and their non-handicapped siblings while parents attended meetings. Large group topics included a discussion of social attitudes, the difficulties and rewards of raising a disabled child, financial and behavioral management, and a demonstration of therapeutic play activities. Small groups focused upon helping parents gain support, understanding and problem solving skills.
Parent Groups, Programs Organized by Professionals


Parent involvement has increased considerably in the last ten years in programs for pre-school age handicapped children, and has been effective in many ways. However, changes in population served, changes in the structure of the family, and role conflicts which have developed between parents and professionals suggest that there are limitations to the approach that has been used. A family systems conceptual framework is proposed as a way to better integrate the whole family into treatment. It is noted that many agencies are still oriented toward providing services for an individual, rather than addressing the whole family system.


The author explored peer self-help psychotherapy groups through a review of the literature, conversations with self-help group members and colleagues as well as observing meetings of such groups as Alcoholics Anonymous and Weight Watchers. The characteristics of such groups are reported. Characteristics include peers reciprocally serving each other as therapists, group members' assumption of a moral position that their behavior is inappropriate and the creation of new relationships which encourage efforts to change. Numerous suggestions are offered to psychotherapists, including recommendations that they refer individuals to peer self-help groups, employ group therapy as their primary therapeutic method and view psychotherapy as a form of social interaction or learning among peers.
Parent Groups, Programs Organized by Professionals


Five prevention programs for children are described. Three of the programs involve families. The PACE (Parent and Child Education) program serves children and mothers who have been identified as having potential parenting problems. Mothers carry out teacher's assistant assignments, review videotapes of their play with their child and participate in discussion groups. BRIDGE camp serves troubled children through the use of the natural environment as its treatment clinic and through use of all camp personnel as "therapists." Problem solving skills are taught through the use of informal parenting groups, family and individual counseling within the home and from assistance in negotiating for services from schools and other agencies. The Montgomery County Community Day School serves young offenders. Families are included in the educational process as participants in frequent family meetings and family therapy sessions. Parents learn adolescent management skills in the "Parent Survival Group."


The study sought to determine the relationships between parent awareness training and parental attitudes toward gifted children and the programs which serve gifted children. Parents of gifted and nongifted children were invited to attend one of two parent education meetings. Parental attitudes varied substantially depending upon whether they attended the parent education meeting. Their attitudes bore a direct relationship to the level of parents' intentions to support gifted education programs. Support for gifted students' educational programs may be enhanced through the use of parent educational meetings.


The Brent Movement arose after World War II to demand better provisions and residential facilities for exceptional children. Research has indicated that early family environment can be crucial in child development, and professionals are now aiming at training parents and actively involving them in remedial programs for home and community care of their children. Two examples of parent intervention programs are given: (1) a Piagetian motor-training to develop cognitive skills in at-risk infants, and (2) a program for older children with reading difficulties. Practical suggestions are offered to help professionals maximally involve parents and promote the success of the program.
Parent Groups, Programs Organized by Professionals


A group treatment program for the parents of chronically mentally ill (mostly schizophrenic) individuals is described. The groups included parents of children who were hospitalized, living in community housing or living at home. Each group began its ten to twelve week sessions with an introductory lecture on schizophrenia and treatment theories. Speakers were scheduled to talk at subsequent sessions on topics chosen by parents. Families were encouraged to spend less time with their mentally ill child, to cultivate community support systems and to establish an independent life for themselves as a couple. Behavioral management techniques were taught. Group results included the implementation of new hospital procedures suggested by parents, more effective parenting and a parent initiated local alliance on behalf of the mentally ill. The local alliance played an important role in the creation of a statewide alliance for the mentally disabled.


A parent education program in learning disabilities is described. The Devereux Day School in Scottsdale, Arizona instituted a program which consisted of six weekly lecture and discussion sessions. The six sessions addressed the following: (1) overview and definitions; (2) laterality and directionality; (3) visual perception problems (4) auditory perception problems; (5) perceptual-motor issues; and (6) summary and review. Subsequent optional sessions addressed specific learning problems and further discussion of individual children.


A parent education program model designed to serve those parents who were sufficiently motivated to attend the first session is described. The initial session had been advertised as "a planning session for a course with a possible focus on parent-child relations, parent tutoring, and community resources." The first meeting emphasized the common problems facing parents of handicapped children and procedures for addressing these problems. A slide presentation described common problems and natural reinforcers for adults and children. Parents completed a questionnaire designed to determine their interests, concerns and strengths. On the basis of the questionnaire, an agenda was planned which included various special topics, guest speakers, slides, films, and discussion periods. Parent progress within the program was measured by recording the statements made by the parents each week and by asking each parent to weekly respond to a written evaluation form which asked "What have you done differently this past week based on the meeting last week?"
Parent Groups, Programs Organized by Professionals


The effects of a training program provided to mothers of handicapped preschool children were assessed. The effects of the program on child skill acquisition, parent-child interaction, knowledge of instructional principles and parental change in attitude was examined. Parents were assigned to either a data keeping or no data keeping experimental group or to a control group. The parent training consisted of four two hour group training sessions. These were followed by four individual parent-child sessions in which mothers instructed their children on skills included on the child's individualized educational plan. Significant changes occurred in some areas. Mothers who had been trained displayed a significant difference on the knowledge test. Marked change in parent-child interactions occurred only for mothers (1) in both the data-keeping experimental group and the no data-keeping group as they reduced the number of instructions given to children following uncorrected incorrect responses and for mothers (2) in the data keeping groups as they increased their use of positive feedback for correct responses by their children. As children in the experimental groups improved, their mothers expressed positive attitudes while fathers expressed negative attitudes. The fathers' negative attitudes may be a result of mothers reducing the amount of time they spend with other family members while working with the child.


As part of a symposium on parent-professional relations in the care of the mentally retarded, this article describes the history and activities of the Parents' Support Program in Denmark. This group was formed to act as mediators between parents and professionals; give support and education to parents, especially at the sensitive time when they first learn of their child's handicap; and to educate personnel about feelings and problems parents commonly experience.


The authors describe a school and day treatment program at the Medical College of Ohio for preschoolers with severe emotional and/or behavior problems. Emphasis is on the involvement of the parent or primary caregiver in the education and treatment of the child. In order to establish a relationship of trust with the staff, parents are involved informally in the beginning. Ultimately, a formal relationship is established through a structured 10-week course called Parent Education and Sharing (PES). The course emphasizes the teaching of a set of skills that will help foster development in their children. Child management issues are also discussed in the course.
Parent Groups, Programs Organized by Professionals


A twice monthly program was organized in 1978 for fathers and their handicapped babies. Information on handicaps and child development, social and professional support, parent-child skills training and meetings with guest speakers were offered, as were special “fathers only” meetings and whole family gatherings. Research was conducted for the purpose of measuring changes in both fathers’ and mothers’ stress and depression levels and support systems. Fathers who had attended the program and their wives all displayed less stress and depression and reported greater satisfaction with social support. Suggestions are given to improve future research projects.


A Minneapolis public day school and research program for mentally retarded children provides a multifaceted program for parents which includes a strong educational component. Mothers participating in the program were questioned concerning the program’s effects and their opinions of the staff and services provided. It was generally concluded that parents primarily need information about mental retardation and their own child. They also need self-understanding to better deal with the stresses of day-to-day life. With respect to child rearing assistance, parents ranked teachers almost as highly as clinical psychologists. Teachers who communicated easily and honestly and who listened were most appreciated.


A workshop for families of schizophrenic outpatients is described. The eight week workshops sought to assist families in exploring community resources, gaining information about mental illness, encouraging participation in their family members’ treatment, teaching behavioral management techniques and encouraging self-help and mutual support among participants. As the groups moved from initially receiving information about the illness to sharing personal experiences, learning management techniques and sharing family responses to the schizophrenia, group members interacted more actively with each other and less actively with the co-leaders.
Parent Groups and Programs: Self-Help


The effectiveness of peer psychotherapy or self-help groups is examined. The author argues that the teachings of a self-help group are its essence. A group's ideology is highly persuasive. Self-help groups tend to possess traits that encourage their members to absorb the group's ideology "as a living reality that is reconfirmed in each day's experience." Alcoholics Anonymous, Synanon and Recovery, Inc. are examined.


This early article discusses parents' moves to create their own self-help support groups. The formation of parents' groups within the March of Dimes is discussed. Parent self-help groups offer families the opportunity to share solutions to problems, to provide support and information, and to educate the community to problems facing handicapped children. Parents offer each other a kind of help they cannot find elsewhere.


The authors examine whether self-help groups represent a social movement, and, if so, what kind. The authors believe the role of self-help groups is ambiguous as, unlike other movements, they do not propose specific remedies to social problems. Social movements are based either on instrumental (obtaining a desired goal) or expressive (personal) satisfactions. The social movement characteristics of self-help groups may vary in degree. Five sequential stages of social movements are outlined and applied to self-help groups. The stages are characterized as agitation at not having one's needs met, membership, affiliation, ideology, and particular tactics.


Many parent groups, particularly those in the area of mental retardation have recently shifted from monitoring services to actual service provision. The author argues for a shift of the parent group role back to advocacy. Advocacy is needed and cannot be performed effectively when a group is caught up in administrative costs and budgets. Service provision should be left to public agencies which have been legislatively mandated to provide services. Parent groups can be effective in changing public attitudes, monitoring service quality, influencing state legislatures and in pursuing needed litigation.
Parent Groups and Programs: Self-Help


The author introduces experiential knowledge as an attribute of self-help groups. Experiential knowledge is defined as "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others." Experiential knowledge is compared and contrasted with the professional knowledge which characterizes the majority of human service organizations. The author submits that self-help groups are not, as many believe to be the case, antiprofessional; rather, they have simply substituted experiential authority in lieu of professional authority. Accordingly, self-help groups are redefined as "voluntary human service organizations of persons sharing a common problem who band together to resolve the problem through their mutual efforts, with experiential knowledge being a primary basis of authority in decision making."


The interest of professionals in self-help groups has focused on three areas: (1) self-help groups arise outside of the professionals' domain; (2) the move to create self-help groups is widespread; and (3) participants in self-help groups find them to be effective. The author suggests that training programs be established for professionals which will assist them in learning to work collaboratively with self-help groups. The proposed legal sanctioning of support groups which would enable them to receive human service or corporate benefits is also discussed.


The author estimates that there are over one half million self-help groups in the United States. Self-help groups are growing in size and number. They serve an extensive array of people with various interests and attributes. He suggests that self-help groups will enable consumers to demand more efficient services. The existence of self-help groups also demonstrates the need for professional service providers to address rehabilitation issues.


Seven ways in which parent groups have played an important role in improving conditions for the handicapped are explored. They include the direct provision of services to children which public agencies were failing to provide, lobbying for legislation and serving as advocates for the handicapped in the judicial setting. The history of parent groups is summarized. Issues facing parent groups in the future (such as whether to work independently or coordinate with other groups and whether to provide direct services versus work to obtain them) are explored.
Parent Groups and Programs: Self-Help


This book is primarily addressed to members of the clergy. Methods of mental health consultation for people in need of guidance and assistance are described. The mental health consultation program which was established by the Harvard Medical School Laboratory of Community Psychiatry and the Massachusetts Episcopal Diocese is examined. Members of the clergy should develop greater objectivity and skill in providing consultive services to members of the congregations.


The following three dimensions of the service provision task of self-help groups are analyzed: (1) a determination of the problems and needs of clients and a determination of how client needs should be approached in planning services; (2) client characteristics and an examination of who is not served; and (3) the characteristics of the direct service environment.


The letter writer enumerates some of the specific goals of the St. Louis Schizophrenic Care and Treatment Society, a self-help group formed by the families of schizophrenic patients. Goals include providing information and referral services for families, advocacy efforts, the collection of data about similar groups and the development of management techniques with and for families.


The author projects the future of the growing self-help movement of families of the mentally ill. She anticipates that the family self-help or consumer movement will enjoy substantial success in the mental health field. Families will influence service provisions, participate in determining priorities and will monitor the services provided to ensure that new policies and services are appropriately instituted. The family self-help movement will produce selective consumers of mental health services. As self-help groups have arisen, in part, as a response to families' dissatisfaction with professionals, mental health professionals must be trained to work collaboratively with families. Professionals should recognize families' strengths and acknowledge their role as the primary caretakers of disabled family members.
Parent Groups and Programs: Self-Help


The author surveyed 71 self-help groups for families of the mentally ill. The article reports the organization, objectives, activities, strengths and weaknesses of the groups surveyed. The author suggests that the emerging self-help groups for families of the mentally ill will have, among others, the following results: (1) service providers will have to justify their services and their expense; (2) as the families of the mentally ill gain strength and authority, theories of treatment and etiology may change; (3) service providers must learn to work collaboratively with families; and (4) professionals must provide more services within the community and offer direct assistance to patients where they work and live.


A consumer advocacy self-help movement has been initiated by the relatives of the mentally ill. The author anticipates that the consumer movement will have a fundamental impact upon the delivery of mental health services. Mental health professionals need to reexamine: (1) their view of families of the mentally ill and perceptions of the family as an institution; (2) their evaluation of natural mutual support systems; (3) professional definitions of mental illness and professional beliefs regarding its etiology and treatment; and lastly; (4) the nature of the relationship between service providers and consumers.


A study to identify the natural support systems which improve one's ability to cope with highly significant life changes is reported. Twenty recent widows and fourteen women over thirty who were newly enrolled full time university students were studied. The receipt of advice, information and explanations (cognitive guidance) was the most important support to the women surveyed. The presence of cognitive guidance was associated with symptomatology and mood. Self-esteem and socializing were significantly associated. Multidimensional friendships and less integrated support systems were correlated with enhanced support and mental health.


The author presents several suggestions for the organization of parental self-help groups in schools. He stresses that parents are the most important advocates their children will ever have, and that parents must often meet to share information among themselves. The author's ideas about the organization of self-help groups among the parents of students can also apply to the organization of similar parental groups in all areas of the community. (Journal abstract, edited)

The author distinguishes peer self-help psychotherapy groups from self-help organizations. Only peer self-help psychotherapy groups have specific psychotherapeutic functions "without recourse to professionals." The writer argues that the self-help movement arose out of the separate religious and secular world views which joined together in the United States. The religious and secular origins are separately traced.


The author asks what role professionals should play in self-help organizations. In the past, professionals were inclined to simply recognize such groups and refer individuals to them. Subsequently, there has been interest in direct participation by professionals in the creation and maintenance of self-help groups. Direct involvement by practitioners does, however, pose problems. Professional participation may do damage to the group's feeling that it can help itself. Alternatively, groups may not be self-help groups if professionals are responsible for their existence and structure. The author suggests that the most challenging role for professionals is that of facilitator. The professional facilitator must be willing to step back once the group is established and allow it to run independently.


The history of the development of the self-help movement in the Western world is reviewed. Among others, the Friendly Society, consumer cooperatives formed at the time of the Industrial Revolution, American colonial mutual aid efforts and trade unions are discussed. Citing their earlier work, the authors define self-help groups and set forth five classifications into which all self-help groups fit. Four issues which affect self-help groups are raised. These include (1) the effect of a change in program goals and (2) the effects upon the participation of group members and the group structure of required ideological orthodoxy versus a tolerance of differences.


The dynamics of self-help organizations are analyzed. Eight structural elements of self-help groups are explored. Among others, structural elements include an expressed group norm of helping others, problem orientation and shared common goals. Four functional attributes (horizontal communication, required personal involvement, individual accountability and an orientation towards taking action) of self-help groups are discussed. Nine self-help group processes and a five stage model of evolution for self-help organizations are also enumerated and explained.
Parent Groups and Programs: Self-Help


The characteristics of self-help groups are listed. Group characteristics include a concern with a specific disease or condition and a desire to provide a particular service. Four factors responsible for the widespread growth of self-help groups since the early 1940's (including a perceived need for mutual support or action and scientific advances which have created better treatment and management processes) are set forth. Self-help group activities are classified as therapeutic, educational, community action, social or legislative.


The advocacy efforts of Parents of Adult Schizophrenics are described. The group learned that successful citizen participation includes identifying the powerful and their motivations and influences, assuming a role in fiscal deliberations, budgeting and lobbying efforts. The authors emphasized that, to insure the success of parents' groups, they should remain apart from the mental health establishment and maintain their separate identities. Family needs, including setting realistic goals for the mentally ill and family assertiveness training, are enumerated.


This article reports the author's "speculations on the psychological processes involved in the activities of self-help groups" based upon observations and a review of the literature. His study was limited to groups which addressed problems which had a significant psychological component and which might be considered adjuncts or alternatives to psychotherapy. He defined self-help groups and developed a typology of four groups based upon their purposes and composition. The author concludes that the effectiveness of self-help groups in aiding their members is extremely variable. Such groups may, however, make a unique contribution to community mental health.


The authors advocate for research addressing the nature of self-help groups and alternative models for viewing their function, growth, and development. They argue that no satisfactory studies of the effectiveness of self-help groups exists. The fact that the usual "pre-post" design is not applicable to many self-help groups renders assessment difficult. Research is also impeded due to the difficulty of gaining entry or access to self-help groups. Professional help-givers and public policy makers must establish a common social policy and research agenda.
Parent Groups and Programs: Self-Help


The book discusses: (1) how self-help groups are initiated and structured; (2) who joins self-help groups; (3) how self-help groups work; and (4) suggestions for evaluating the effect of self-help groups.


The formation of the National Alliance for the Mentally Ill in 1979 is described. The group seeks better treatment of the mentally disabled, increased research into mental illness and an increased involvement by families in the treatment of their mentally ill family member. The organization’s membership includes families of the mentally ill, mental patients and former mental patients.


Parent organizations for the mentally retarded were formed in response to parent dissatisfaction with services and professionals’ attitudes and treatment. Professionals were perceived as distant, unrealistic and unwilling to relate to families’ practical concerns. The origin, history, organization and self-definition of the National Association for Retarded Citizens are traced. Descriptions are given of local chapters’ activities and their relationships to the national organization. An evaluation of impact and effectiveness of this association is made. Recommendations concerning controversial issues such as: (1) the involvement of lower income people, (2) parent versus professional memberships and (3) providing versus obtaining services are offered.


This guide is written for mental health workers in order to increase their awareness and to provide them with information about mutual help groups. The topics covered are: (1) the definition of mutual help, (2) periods of critical transitions, (3) the nature of help and its characteristics, (4) specific groups and what they do, and (5) the mental health worker’s role with mutual help groups.
Parent Groups and Programs: Self-Help


Individuals pass from one role to another and find themselves in transition during the normal life cycle. Where society itself is in transition or formal rites of passage do not exist, the individual has no guidelines to follow when attempting to cope with such a role change. Mutual-help groups can provide direction. Helpers who have successfully coped with the transition themselves serve as role models and teachers and can help link individuals in transition with appropriate community resources. The three stages of transition which are commonly observed in the bereaved and in disaster victims are discussed. The results of a study of La Leche League are reported.


The book is aimed at human services professionals who are either organizing a self-help group or are contemplating doing so. Professional attitudes which may either hinder or help efforts to assist in the development or maintenance of self-help groups are examined. Guidelines for organizing mutual help groups and for maintaining and managing them over time are offered.


Forty-eight self-help organizations were studied to test the authors' hypothesis that self-help organizations tend to reject professionalism and bureaucratization (which are primary features of service organizations) in favor of autonomy and solidarity (which are primary characteristics of mutual benefit organizations). Criteria which define self-help organizations are set forth. The authors concluded that self-help organizations bear a greater similarity to mutual benefit organizations than to professional human service bureaucracies. Seven methods by which self-help organizations act to preserve their autonomy and solidarity are identified. Methods include challenging professionals' beliefs that treatment rests exclusively in their domain and developing self-help networks for the delivery of services which are designed as alternatives to professional service delivery systems.


Using data from a survey of 330 parents of developmentally disabled children, this paper examines parents' participation in and attitudes towards special interest groups and political activities. Findings indicate that parents are willing to participate in special interest groups and political activities to a much greater extent than they have actually done. Organizational involvement is contingent upon the amount of stress experienced by the family, indicated by age of child, severity of the disability and family income. (ERIC abstract).
Parent Groups and Programs: Self-Help


Traditional primary small groups have tended to wither away due to the pre-emption of social functions (hunting parties, barn-raisings, etc.) by large impersonal institutions. Consequently, individual needs for support remain unsatisfied and problems are created which exacerbate people's needs for group support. Public policy would best be served by strengthening self-help and cooperative groups and recognizing that groups which support people protect their health and ultimately their general welfare and national productivity. Methods of strengthening traditional groups such as families, churches and neighborhoods are explored. The author proposes the passage of legislation to incorporate families as well as self-help groups.


The authors studied the relationship of social workers to the self-help movement. Forty-four self-help groups were surveyed to determine group characteristics, attitudes towards professionals, level of professional involvement and group goals. The study revealed that social workers were more likely to be involved in the creation and development of the groups studied than were other professionals. Among other roles, social workers can assist self-help groups by offering material support such as money or a meeting place, bridging self-help groups with clients and other services, acting in a consulting capacity and assisting with the initial start up of a self-help group. The self-help groups surveyed generally displayed a positive attitude towards the involvement of professionals in their groups.


Almost 250 social workers were surveyed to determine the factors which influence their use of self-help groups as a resource for their clients. Social workers' use of self-help groups is influenced by a number of factors, including: (1) their knowledge of self-help groups; (2) their attitudes about such groups; (3) the policies, procedures and practices of the social service agencies; and (4) the reception social workers receive from self-help groups. Social workers need to be informed of the availability of self-help groups and of their potential use as community resources. The relationship between social workers and self-help groups may be improved by establishing a referral system to self-help groups, maintaining current directories of local self-help groups, and offering professional consulting services.
Parent Groups and Programs: Self-Help


Self-help groups are categorized as: (1) those which offer direct services such as coping skills, education and peer support to patients and their families; and (2) those which focus upon public education, lobbying, fund raising and research. The results of a two year collection of data on self-help health organizations are reported. Self-help groups can assist members in adapting to a new illness or disability, offer direct services and educate professionals.


The authors describe the history of the voluntary self-help movements and suggest that its rapid growth may be attributed to the fact that self-help groups create a feeling of autonomy and solidarity among their members. The results of a study of 48 self-help groups indicate that such groups have greater peer or horizontal service relationships, offer greater mutual aid and a wider variety of services than do human services organizations.


The author asks whether self-help organizations should "be recognized in official public policies as were the community action groups in the federal legislation of the 1960's?" Self-help groups often serve as the link which connects individuals with professional human services. The public policy difficulty is to determine how to encourage constructive self-help organizations and how to eliminate or reduce those organizations whose impact is negative. The author suggests that public policy should not assume responsibility for constructive self-help organizations, nor should it offer direct support for members' activities. Self-help groups may be encouraged by promoting publicity about them, by creating nongovernmental bodies which offer assistance to self-help groups and by providing technical and professional assistance upon request.

Self-help groups are defined as "groups that emphasize the power of their members to assist one another rather than depend on the help of professionals." Their development is an outgrowth of peoples' interests in meeting their own needs and deciding the course of their own destinies. The emerging role of clients in service delivery is regarded as a social movement. The author explores the social (welfare rights groups, community organizations) and clinical (Alcoholics Anonymous, Synanon, etc.) uses of "client power" and the implications of the movement for the professional community. Professionals can assist self-help groups by serving as facilitators during the group's early growth, researching group problems and offering suggestions for the group's further development. Seven implications for professional education are offered. Suggestions include training professionals to be facilitators and researchers as well as teaching professionals to self-disclose to clients when it is appropriate. The emerging self-help movement suggests that clients should be viewed, not as service recipients but, rather, as colleagues.


The organization, "Parents of Adult Schizophrenics" of San Mateo, California is described. Members of the organization tend to place little confidence in "talk" therapies. They favor holistic approaches to the treatment of schizophrenia and particularly emphasize work, exercise and diet. Monthly "woe" meetings are held in which members may share common experiences. Experts are invited as speakers. In their efforts to improve the care for schizophrenics, members of the organization are politically involved through lobbying efforts, letter writing campaigns and service on legislative task forces. Their efforts have had demonstrable beneficial effects.
Parent Participation in the Helping/Educational Process


The authors provide the results of a multivariate study which explored 22 possible factors related to parents' interest in their institutionalized retarded children. Parental interest was measured by the frequency of family visits to the institution and attendance at parent conferences. Six major predictors for parents' lack of involvement with their children are identified. They are: (1) the custodial parent being divorced and remarried; (2) the father's occupational level being low; (3) the child having physical anomalies; (4) the parents living a greater distance away from the institution; (5) maintenance payments not being required; and (6) the disparity between age and social maturity being higher.


The author suggests that changes in the family system will enable a person recently released from a psychiatric hospital to employ newfound skills and to reduce the likelihood of rehospitalization. Family involvement in treatment alters their response to crises and enables the patient to use his new insights and abilities. Obstacles related both to families and to hospitals are discussed. Family-related obstacles to involvement include the family's belief that their responsibility is suspended upon the patient's hospitalization and their withdrawal from the institution and the patient. Families may also take the position that there is an identified patient who is ill and that the patient, not the family, is in need of treatment. Hospital related obstacles to family involvement include the disease model of diagnosis and treatment as well as traditional hospital policies and practices that foster a focus on the individual patient and do not recognize the potential role of family members. Staff can enhance the probability of family participation by encouraging involvement during the admissions process, by enabling the family to spend time with the patient, by gathering data about the patient and his/her conduct from the family, by not overemphasizing the role of family dynamics in causation and by adopting a consistent team or staff plan of action with each family.
Parent Participation in the Helping/Educational Process


The authors report the results of two studies. The social networks of both low income and high risk populations were examined to determine why these two populations have a low level of participation in preventive human services programs and a high dropout rate. The first investigation studied high risk women who had been referred to a parent education program. Women with more dense social networks attended fewer parent education group sessions. The second study examined low income women who were involved in a supplementary food program sponsored by a public health agency. Participants who had less dense social networks and fewer contacts with their relatives were more inclined to seek professional parenting information than were women from more socially dense, family involved settings. The overall frequency of parent information-seeking was determined by the interaction between the study participants' social network and their sense of competence as a parent.

*Brinckerhoff, J.L. and Vincent, L.J. Increasing parental decision-making at their child's individualized educational program meeting. Portage, WI, Portage Project, Madison, WI, University of Wisconsin. Manuscript submitted for publication.

The legal requirements of parent participation in the school decision-making process may be interpreted differently by parents, staff and school. In order to develop ways for schools to improve parent participation in individual educational program (IEP) meetings, a study was set up with fourteen families of developmentally disabled children. It was concluded that, even with relatively little training of both school personnel and parents, significantly greater parent participation was noted. It remains to be measured how effective greater parent participation is for children's development.


The authors describe the involvement of parents with their psychotic children in a day treatment program. The intensive milieu treatment programs include individual therapy, education, recreation, small therapy groups, and daily activities. Also discussed are the problems encountered in implementing the parent involvement component, staff attitudes and reactions. In order to maximize the benefits for parents and child, the program emphasized a fully integrated psychotherapeutic and psychoeducational program as well as the achievement of an effective synthesis between the individual psychiatric treatment and the optimal use of the milieu.
Parent Participation in the Helping/Educational Process


The focus of this paper is on parent involvement with their handicapped children’s education in a multidisciplinary team process. The authors explore seven advantages of this involvement, and suggest strategies to maximize the quality of parent participation. Public Law 94-142, the Education for All Handicapped Children Act, is explained.


A study investigated the degree of correlation between the locus of control and involvement of mothers in the day treatment of their emotionally disturbed children. The sample consisted of 42 mothers whose children attended a residential day treatment center. Findings confirmed the hypothesis that mothers who believed in their ability to influence events in their behalf were likely to be involved in the treatment of their children. Conversely, mothers who believed that they were powerless were not likely to be involved in the treatment process. An important treatment implication derived from the study was the importance of engaging the mothers as full partners with the agency in the provision of services for their children. A theme underlying the suggested treatment approach is the empowerment of the mothers, both in their maternal role and in their interaction with the agency. (Author abstract, edited).


Forty-five parents of learning disabled children were randomly divided into three groups. The first group of parents were sent questions prior to an individualized education program (IEP) meeting concerning their goals for their child, the child’s academic potential and the development of an IEP. The second group had the school guidance counselor present as a parent advocate at each conference. No intervention occurred with the third group. The level of participation of parents who received questions prior to the conference was not significantly greater than that of the control group; however, more fathers who had received questions attended the conferences. Parental participation increased where a counselor was present as a parent advocate. The two strategies may easily be implemented and may increase parental input and attendance at IEP conferences.
Parent Participation in the Helping/Educational Process


Individualized education program (IEP) conferences were studied to determine parent and teacher participation, topics discussed, conference length and participant satisfaction. It was found that the resource teachers tended to participate more than the regular classroom teachers; that parents tended to be passive recipients of teachers' already prepared plans; and that there was an unanticipated positive satisfaction level on the part of all participants. In conclusion it is suggested that training be developed for both parents and professionals, that parents participate more in the development of education programs for their children, and that professionals educate and work more cooperatively with parents.


Project Partnership was created in Massachusetts to improve parent-professional relationships in the education of special needs children. This program's philosophy is to be flexible and recognize individual needs and differences in parent-school programs. A wide range of techniques are available to provide change both at home and in the school, including: (a) team trainings on a variety of topics for families, educators and administrators; (b) parents trained to be leader-coordinators in each classroom; (c) stipends to parents for time and participation; (d) mini-grants to support parent programs; (e) co-teaching; and (f) practical and flexible behavioral strategies to improve home-school cooperation. Evaluation of the program revealed participant satisfaction and increased family-school contacts. Dilemmas encountered are discussed, including possible hidden or negative messages to parents that a program like this can communicate and the possibility of increased unnecessary burdens on teachers.
Parent Participation in the Helping/Educational Process


This paper discusses ways parents influence the educational and emotional development of their handicapped children and how parent involvement in special education programs facilitates growth processes in these children. Research findings indicating the importance of the parent-child relationship and parenting styles are summarized. Program descriptions are presented and suggestions are given for implementing aspects of parent involvement in programs designed to meet the needs of handicapped children. Included are discussions of the desire for varied program approaches to meet individual parent-child needs; language delay and creative programming in the home; child abuse problems and solutions; severe emotional handicaps in children and how parents can help; the need to provide information for parents (on their children's handicapping conditions, on various types of programs and the theories on which they are based, and on mainstreaming possibilities) to help them make decisions as to the best placement for their children. Advantages of parent-to-parent models which provide opportunities for parents of handicapped children to talk and work together are discussed along with programs focusing on the prevention of childhood handicaps through parent education; educational resources for parents; and parental characteristics and behavior which are likely to promote optimum development of handicapped children. (ERIC abstract)


A program model for communicatively handicapped youngsters is described. The parent program consisted of an intensive program for mothers who could accompany their children to the program daily. A workshop program was designed for those who could not participate on a daily basis. Mothers who participated in the intensive group observed lectures and films on normal child development and communicative handicaps. They learned behavior modification techniques, participated in their children's recreation programs, participated in group sessions with a psychologist and awareness groups with a social worker and met individually with a staff psychologist. Mothers assisted in developing learning packets for use in assisting their child's rehabilitation process within the home. Those parents who participated in the workshop program attended three training sessions which focused on (1) normal development; (2) speech, language and hearing problems; and (3) behavior modification techniques. Parents received individual counseling with respect to the children's communication problems and observed their child's participation in therapy. Follow-up was provided for both intensive group and workshop group parents.
Parent Participation in the Helping/Educational Process


A systems approach may be employed in an effort to obtain family involvement in agency programs for exceptional children. An eleven stage model is described which conceptualizes the complex assessments and interventions needed to involve and interrelate all parts of the system of child, family and agency. Parents are seen as decision makers with agency staff in the role of consultants.


The pros and cons of parent involvement in special and general education are studied. Many writers have discouraged involving parents, citing the complexity of present day school systems and teaching methods, and essentially blaming parents for mismanaging their children. However, it is noted that parents themselves have been primarily influential in pressing public policy to create present educational programs. Especially in special education, many parents are now reaffirming the importance of the family to school progress and encouraging working with parents in a variety of ways to link school and the home.


Specific guidelines designed to make individualized education plan conferences as productive as possible are offered. Parents and professionals should have the goal of acting in partnership on the behalf of children. The objectives of the meeting should be drafted in advance and sent to all participants. Parents should be provided with advance information regarding meeting procedures, biographies of staff members and a glossary of frequently used technical terms. Parents should be encouraged to invite another parent or professional to the conference who may offer advice or help clarify matters. Meeting times should be flexibly scheduled. The participation of all who attend should be encouraged. Meetings should last no longer than one and one-half hours. The author recommends that four conferences should be scheduled for each school year.
Parent Participation in the Helping/Educational Process


The paper discusses the rationale and guidelines for parent involvement in HCEEP (Handicapped Children's Early Education Program) projects. Ways of assessing parents' needs are reviewed, as are four types of services to meet the identified needs: parent education, direct participation, parent counseling, and parent provided programs. Materials and approaches are recommended for each of the four delivery types. The parent education approach is considered in terms of teaching parents to participate in individualized education program planning, and providing information on such topics as normal growth and development and special skills needed to provide care for their child. The description of the direct participation approach focuses on work with fathers, and new approaches such as the Portage Project. Parent counseling emphasizes coping patterns and lists criteria for successful counseling. Parent organizations and parent to parent programs are sources of parent provided programs. A section on evaluation of parent involvement programs touches on ways to measure parent satisfaction; program effectiveness; changes in parent knowledge, skills, and attitudes; and the degree to which services are used. (ERIC abstract).


Thirteen parent intervention programs for the handicapped and twelve parent intervention programs for the disadvantaged are reviewed. The writers concluded that paraprofessionals were often employed in programs for the disadvantaged, while programs for the handicapped tended to use only professional staff. Parents of the disabled had a higher rate of participation in school activities than did parents of the disadvantaged. Five suggestions were offered. Suggestions included a recommended examination of the benefits paraprofessionals could make in programs for the handicapped and the design of parent intervention programs for the parents of the handicapped.


This book is addressed to educators. Strategies for heightening the effectiveness of parent conferences are described. The authors emphasize work with parents of preschool through junior high school children. Training exercises are offered in the following areas: the exploratory or information gathering conference, communicating test results, follow up conferences and staff member defensiveness. Public Law 93-380 (the Education Amendments Law of 1974) is explained.
Parent Participation in the Helping/Educational Process


The study examined the involvement of parents of special education students in the school decision making process and also examined the level of involvement in school decision making which parents would like to have. Parents most often find that they give and receive information. Secondly, they find themselves in the position of having no involvement in the decision making process. Lastly, only infrequently do parents find that they have control over the decisions made. Parents want to play an informational role in decisions made with respect to discipline, evaluation, class placement, instructional groupings, special resources and transportation. Parents would generally like to have decisional control over medical services for their children, the type of information retained on their child and the transfer of their child to another school. The shared view of parents and professionals with respect to who should assume the educational decision making responsibilities, should form the basis for cooperative planning for children.


The author argues that maximizing parental involvement in special educational services for handicapped children requires special educators to carefully prepare for their initial parental contact. Before contacting the parents educators should gather as much information as possible about the child and the family. Such information can help the professional determine whether to call, write, or personally contact parents to arrange for the initial home visit. Professionals should dress in a manner which puts the family at ease. Each contact should include making arrangements for the next visit in an effort to ensure ongoing family involvement.


The greater participation of parents in the education of handicapped children has created the need for more information and guidance for families and educators. This book includes chapters by experts covering such subjects as: (1) strategies for working with parents; (2) what being a parent of a handicapped child is like; (3) ethical issues; (4) social policies; (5) the law; (6) the educational system; and (7) the future of special education.
Parent Participation in the Helping/Educational Process


One thousand psychiatric emergency hospital patients were studied to ascertain whether the family played a role in the patient's psychiatric emergency. The study examined: (1) whether family members accompanied the patient; (2) whether a family issue seemed to be involved; (3) whether the family participated in disposition plans; (4) whether a referral for family treatment was made; and (5) whether the services of a family crisis therapist who could have been made available to the family within 24 hours would have been of assistance. Statistical results are reported. Slightly more than one half of the patients were accompanied by members of their families and an additional 5% were subsequently joined by their families. Clinicians believed that more than two-thirds of the psychiatric emergencies were related to family matters. Accordingly, given the prevalence of family members' presence and problems, clinicians should recognize families as a potentially helpful resource.


The parent involvement program at Smallwood Center, the children's unit of Moccasin Bend Mental Health Institute (a Tennessee state psychiatric hospital) is described. Parents are required to participate in their child's treatment because: (1) studies have repeatedly demonstrated a relationship between children's behavioral disorders and parental child rearing practices; (2) as parents learn new child management techniques they will apply these techniques to their other children and thereby avoid problems with those children which ultimately enables professionals and limited funds to serve a larger population; and (3) studies have demonstrated that parents can effectively cope with their children's behavioral problems when they receive proper training. Parents are expected to attend weekly parent group meetings, to employ the parenting techniques they learn with their child and to report on the child's behavior within the home environment. Parents learn three major ways in which social learning occurs (modeling, ignoring and positive reinforcement) and are also taught three basic child management techniques (contingent rewards, positive reinforcement and ignoring). Techniques for teaching parents include group discussion, lecturing, role-playing, behavior rehearsal and designing contingent reward systems. Following a child's discharge from the program, a liaison staff member remains indefinitely available as a resource to the family.
Parent Participation in the Helping/Educational Process


A case history is presented of two parents who express their dissatisfaction with the individual educational plan (IEP). The parents felt that they were railroaded into signing it, that the school did not keep them informed of their child's progress, and that the plan had not been carried out. The classroom teacher replied to the parents' charges and detailed her own frustration with the school's difficulties implementing the plan and the conflicting demands of various special education personnel. It is recommended that parents bring a professional as an advocate with them to IEP conferences, particularly at stressful end-of-year decision times.


The book is designed to teach parent conferencing skills to teachers of exceptional children. Extensive role-playing materials are offered in the areas of (1) initial interviewing; (2) behavior management; (3) individualized education programs; (4) progress report conferences; and (5) conflict resolution conferences. Specific attention is paid to minority, single parent and reconstituted families.


The study explored the attitudes of families of hospitalized mental patients toward family involvement in treatment. Two-thirds of the 23 family members displayed concern, knowledge about treatment and the patient's condition and an inclination to participate in treatment. Clinical staff members, however, demonstrated internal disagreement and disagreement with families with respect to certain treatment variables. The author recommends that inservice training and visits to facilities that have family involvement programs may enhance staff commitment to family participation. The purpose of family therapy should be explained at admission interviews with the family. Home visits and discharge plans should be made dependent on family meetings.


Despite improvement in parent participation in recent years, many parents still drop out from home and school based programs for exceptional children. This often has detrimental effects on family and child. A number of factors that may predict parent attrition are identified. Four types of high risk families are described, and strategies to improve parent long term involvement are provided. A table reviews parent attrition data reported in the literature.
Parent Participation in the Helping/Educational Process


Regional Resource Centers were established as part of P.L. 91-230 to be centers for information and research on programs for handicapped children. This report surveys parent-school relationships as mandated by law, the historical background, the legal view and present day practices. Implementation of equal parent-educator collaboration has been difficult, as many parents are not prepared, many educators and parents do not feel it is worth the effort, and many parents remain apart or only tokenly involved in their children's education. Two solutions are offered: (1) to provide greater awareness and information of the benefits of parent-educator partnership, and (2) to improve parent involvement by giving partnership training for both educators and parents. Regional Resource Centers are suggested as a good possible source for these trainings.


The author reviews assumptions about parental participation in special education for their children which went into the writing and enactment of P.L. 94-142. This law is described as one which "revolutionized special education" by assuring the participation of parents in their children's education through planning, challenging evaluations, obtaining the power of consent over evaluations or placements, and accessing educational records. Besides participation in their children's education, the law enables parents to hold schools accountable. The author examines the assumptions underlying the legislative mandate and recommendations that parental participation is beneficial to all concerned, and that schools need to be evaluated. Finally, the author addresses a threat posed to parental participation "under the guise of deregulation." It is suggested that a return to state and local administration would be detrimental to these recent gains made for special education.


The term "parent programming" describes "a subset of parent involvement which includes only direct services provided to parents. These direct services may include assistance given the parent in managing his/her personal and family life as well as assistance in developing knowledge, skills and attitudes needed for educating and rearing a handicapped child." The development of parent programming involvement requires professionals to first determine the competencies needed by the parents of handicapped children. Secondly, initial competency levels must be assessed, and programming must be individualized for all parents. Lastly, appropriate learning experiences for the competencies which have been selected must be presented to parents. Parent programming involvement in handicapped children's service delivery systems may take the form of parents serving as disseminators, project evaluators, advocates and teachers of their own children.
Parent Participation in the Helping/Educational Process


Family participation in education of handicapped children is reviewed here for the purpose of providing both a historical and legal summary and to discuss present activities and problems. The special needs of families with a disabled child are described and specific suggestions are offered to improve program design and evaluation to better serve parents and children. A table is provided listing assumptions made by parents and professionals which detract from the establishment of collaborative relationships.


This paper presents the major findings from a survey on parent participation in decision-making that was distributed to school administrators, trustees, and a random selection of teachers and parents at School District #68 in Nanaimo, British Columbia. The study was designed to explore means of facilitating partnership between parents and schools in the current sociological and technological context. Color-coded questionnaire forms were distributed to parents, teachers, administrators, and trustees, with questions relating to (1) general identifying information, 2) school community relations, (3) instructional services, (4) personnel, and (5) "free response." General findings are reported for each group surveyed, and tables are provided that show statistical profiles of respondents in relation to questionnaire items. Twelve of the questions asked were similar to those on a 1979 Gallup poll, so results of that poll throughout Canada and in British Columbia are compared with these survey results. Twelve implications are derived from the study as a whole, suggesting that parental involvement in schools is favorably regarded but requires careful planning and cooperation by all groups involved. (ERIC abstract).
Parent Participation in the Helping/Educational Process


The author describes a research project called the Parent Involvement in Education Project which is based on the idea that parents and teachers need to develop a more collaborative relationship for the quality of education in the public schools to improve. A written questionnaire was distributed to determine attitudes, roles, and current practices of parent involvement. One of the goals of the project is to use the information to develop strategies and guidelines for teacher training in parent involvement. The results showed that more parents and educators accepted the idea of parent involvement, though differences did occur between the two groups in regards to certain aspects. Both groups cited a need for teachers to be trained for parent involvement. Several recommendations are listed to promote effective parent participation in the education of children at home and at school.


Parents' views of their involvement with a pre-school program for handicapped children were studied using a focused interview and a questionnaire based on issues raised in the interview. Results indicated that parents wanted a break from educating their children at home and thus appreciated sensitivity and competency in teachers. Also, parents valued not being formally involved in their children's education at times, and indicated they favored frequent informal contacts with teachers. The implications for planning and research are that parent involvement with their children could be distinguished from involvement with the programs, and a more flexible and individualized conception of parent services can be used.


Children's special education eligibility and programming decisions are made at planning team meetings. Connecticut planning team members were surveyed to determine their attitudes about the types of planning team activities in which they believe parents should participate. A majority of the planning team members believed parents should play the role of gathering and presenting information relevant to their child's case. Less approval was found among the planning team members for parental participation in reviewing the child's progress or the appropriateness of the child's program, or participating in program development. Planning team members expect parents to provide information but do not expect them to participate in active decision making. Such attitudes on the part of professionals may determine the role parents will play in their children's special education program. If parents are allowed to assist in the decision making process, parental cooperation and support of the program may be increased.
Parents as Aides, Helpers and Therapists


Parent volunteers were trained as teacher aides in a primary classroom for thirteen mentally retarded children. The program sought to individualize children's instruction, encourage parental involvement in their children's education both at school and at home and promote the interest of the community. Most parents worked with their own children. At the end of 8 1/2 weeks each child had progressed beyond what would have been expected without the individualized attention. Parental interest in their children's school progress increased. Parents began working with their children at home, requested additional home projects, became involved in after school activities and successfully solicited community donations.


Forty-one educators who worked in innovative education programs for severely and multiply handicapped children responded to a questionnaire designed to measure support for parent participation in the education of handicapped children. Generally, the educators were supportive of parent participation. The educators were, however, opposed to using parents as teaching assistants in their own children's classes and were skeptical about the advisability of using parent to parent training.


Sixty families of chronic schizophrenic patients undergoing treatment with drugs and social therapies were studied to determine their potential role in the patients' rehabilitation and discharge. Many of these families maintained an active interest in the patients, expressed in continuing visits to the hospital. Their attitude toward the patient's illness was optimistic and many families favored discharge. Their expectations were realistic and in accord with the patients' capacities. Their ability to help the patient was compromised by low annual income, insufficient room at home for another family member, and inability to help the patient find a job. The importance of the increased use of the psychiatric social worker and of additional community resources was emphasized.
Parents as Aides, Helpers and Therapists


Human service agencies must create new resources in order to meet the ever expanding demand for their services. Attempts to meet existing demands for services, however, often have the effect of increasing the volume of requests for assistance. The provision of resources by human service agencies may be expanded by using professionals as consultants, using other resources of the larger community and redesigning work requirements as a group of separate and discrete tasks rather than relying upon general job descriptions. The author argues that the growing demand for human services can only be met by additionally employing the following strategies: (1) paraprofessionals, noncredentialed, indigenous workers must be employed which will both enable agencies to reach persons who have not previously been served and will enable agencies to more effectively use their professional resources; and (2) the helper principle should be applied which would enable service recipients to become service providers (example: prisoners tape record books for the blind).


Most severely handicapped children are now raised in the home. Parents often experience great difficulty in the time period between first learning of their child's handicap and entering the child in school. It is suggested here that parents can effectively act as therapists for their children in these years. Parents may perform many of the tasks of early intervention and can strengthen the parent-child tie. The literature is reviewed with respect to parents and behavior modification, methods of home intervention, evaluation of parent therapy and overall effects of intervention programs which employ parents as therapists upon the family.


Parents of pre-school and school age mentally handicapped children in Great Britain were trained in behavior modification techniques and in the use of video tape recording (VTR) systems. The video system was designed to ease communication and supervision between psychologist and homes. Problems encountered by the group over a four year period are described, along with suggestions for solutions. In conclusion it is recommended that a parents' group include either home visits or a VTR system, that there be a variety of supportive activities, that groups be formed of parents with similar child's abilities, and that there be parent-school participation from the start to prevent conflict.
Parents as Aides, Helpers and Therapists


New treatment modalities for persons with mental illness have brought the family into the picture as the primary care-giving institution. Families are turning to mental health professionals for assistance in becoming more effective caregivers for their disturbed relatives and in coping with the many problems that develop. Professionals are not now prepared to provide families with appropriate help, as is evidenced by the findings of little congruence between what families want from therapy and what they get. This calls for a new look at training and at the theory and research upon which training is based. This is a propitious time for change. Many of the articles cited in this chapter indicate considerable restlessness within the professions, and there is a strong voice outside the professions in the rapidly developing consumer movement that is beginning to articulate its desires for new directions. (Author's summary, edited).


For learning disabled and emotionally disturbed preschoolers, parent-staff partnership is considered to be the most effective means for integrating children into the communities of family, school and peers. The short-term psychiatric center for preschoolers which is described involves parents not only in educational roles but as principal therapists for the child. The parent program uses three main modalities: parent education groups, family demonstrations where parents can observe children in sessions with a therapist, and parent counseling and family evaluation. The steps taken to involve parents are described, and some of the obstacles the program has encountered are discussed. Obstacles include the staff consciously or unconsciously blaming parents from a psychodynamic viewpoint (and thus blocking parental participation subtly) and also parents’ expectations of being kept in an unimportant role and parental resistance to assuming leadership in their children’s program. Finally, there may be community resistance to integrating disabled children into regular classrooms.
Parents as Aides, Helpers and Therapists


A parent-therapist program designed to serve emotionally disturbed children is described. Foster parents are viewed as the primary treatment resource. Foster parents acquire specific therapeutic skills and an enhanced understanding of psychodynamic issues as well as learning specific behavior management techniques. Each of the parent-therapist couples interact with one another and with the children in each other's care, thus enabling each foster family to offer respite opportunities to other foster families. Foster parents may also serve as "therapists" for the natural families of children in their care. The program is unique in two respects: (1) the foster parent-therapists and their families assume primary responsibility for the treatment of the children in their care and (2) the support for parent-therapists is provided not by professional caseworkers or therapists, but by other parent-therapists (foster parents).


The study examined the behavior change of parents and their developmentally delayed preschool children during an intensive experimental communication/language training program. Parents attended ten weeks of training and kept daily records of his or her child's home training sessions. Parents learned to plan and carry out student lessons and to encourage their child's language development. Parents significantly increased their use of five strategies designed to stimulate language development. The present study demonstrates that parents' communicative behavior can be altered through instruction in the use of specified teaching strategies.


Seventy articles written between 1965 and 1974 which employed behavior modification principles to aid parents in managing their children are reviewed. The author emphasizes methods of producing change in parental behavior. The following areas are reviewed: (1) historical development of parent training in behavior modification; (2) technological issues relevant to pursuing parent training programs; and (3) the research procedures employed to develop and assess the technology.
Parents as Aides, Helpers and Therapists


The Parent Training Program component of the Judevine Center for Autistic Children's program is described. The three week program seeks to assist parents in independently training their children. Parents learn basic operant and specific social exchange principles and also learn behavior management and problem solving skills through supervised practice. Sixty-nine printed modules teach the skills that parents are expected to learn. Skills are generally presented to parents in the following sequence: (1) lecture; (2) parents observe others implementing the skills; (3) parents assist a trainer in the use of the skill; (4) trainers assist parents in using the skill; (5) parents apply the skill without the trainer being present in the treatment room. Trainer follow-up is provided. The Day School Learning and Treatment Center component, which is designed to provide children with the skills needed to satisfactorily perform in a regular classroom setting, is also described.


Increasingly, professionals are recognizing the value of parents as teachers for their handicapped children. Animal and human studies are cited giving support and rationale for this position. Many types of parent training programs and the problems encountered are examined, as well as factors which contribute to effective symbiotic parent-professional partnerships. Both home based and center based programs are analyzed. In general, behavioral techniques are concluded as most effective for parents to learn and use with children. Three factors are described as crucial in forming egalitarian parent-professional relationships: (1) provision of emotional support; (2) improving communication, empathy and information exchange; and (3) improving parental teaching strategies. A list of over 200 references is provided.


This paper describes a model for working with disadvantaged families whose children do not benefit sufficiently from a pre-school experience to perform adequately in elementary school. The model was used on a pilot project in Chicago which served a lower-income, black, public-housing community. The aim is to create a family environment in which children's competence development becomes a part of everyday life. The worker introduces concrete activities to families, works with them in their own homes and serves as a role model. The parent's values and beliefs are learned from an initial interview and used as a framework by the worker. The operating principles and action phases used in this strategy are described. An emphasis is placed upon the parents' role as teacher/developer rather than controller.
Parents as Aides, Helpers and Therapists


Parents are becoming actively involved in exceptional children's education and are not only improving their own skills for working with children but are creating changes in the educational system. Parent roles as teacher, advisor and advocate are described. Major contributions and changes brought about by parent participation are noted.
Parents' Problems, Needs and Characteristics


Questionnaires were completed by 217 parents of handicapped children to determine their present level of involvement and their desired participation in the education process. Among demographic findings were that of the 74 percent of parents who reported their child's needs were being met, rural parents expressed the greatest satisfaction with services; that there was unexpectedly low agreement between parents and districts on the category describing the students' handicap; that 87 percent of parents were not presently involved in the local school; and that 32 percent felt no one provided them with assistance and/or advocacy. Among parent preferences for ways to improve communication with the school were regular letters and school conferences, with home visits ranking lowest. Parents expressed greatest interest in becoming involved in their child's progress reviews. Two general conclusions were drawn: that parents appear to be pleased with their children's services, and that it appears to be a question of personal preference rather than group characteristics which dictates parent needs and attitudes regarding advocacy. (ERIC abstract).


Programs for the mentally retarded and developmentally disabled increasingly focus upon home care, yet many of the day-to-day needs of parents and families have been overlooked. This policy review for New York State covers the historic background, demographics, progress and effect of deinstitutionalization, impact on families of long term home care, and assesses families' needs in view of present services. Policy suggestions are developed for providing relief to families in the form of respite care, financial aid to increase purchasing power, and to improve flexibility and access to service benefits through a voucher system.

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Parents’ Problems, Needs and Characteristics


Fathers of mentally retarded children demonstrated depression, preoccupation with their child, a feeling of relative inferiority as fathers, limited enjoyment of the disabled child, and a lack of overall gratification with their relationships with their wives and other children. Additional data suggested that the father of a mentally ill child is "a constricted male accentuating his compulsive tendencies in order to suppress his aggressive and sexual drives." Traditionally, the fathers of the handicapped spend more time away from their children at work than do their mothers. Consequently, they play a limited role in "rehabilitative or health-maintenance" tasks such as doctor or school visits and thus lack many of the opportunities for counterbalancing the anger, frustration and sense of loss they experience. The author argues that mental health professionals and organizations for parents of handicapped children offer fewer services to fathers and opportunities for social sharing of the experiences than are offered to mothers. Accordingly, fathers have a more difficult time reducing their level of stress.


This article recognizes the recent encouragement of advocacy for the handicapped arising from legislation in the 1970’s. The actual practice of parental advocacy for disabled youth is questioned, however, particularly where parents and handicapped children may experience conflicts of interest. These would be normal conflicts that would arise for any teenager, but which are complicated for the disabled teen by a family which has incorporated the disability into its structure and refuses to let go when adolescence is reached. Four typical conflicts are detailed (independence, peer group identification, sexuality and goal setting), and it is suggested that the disabled individual who struggles through this and advocates for self is taking valuable steps into adulthood and maturity.


The families of hospitalized schizophrenics were studied to determine their potential emotional resourcefulness for their mentally ill family member. Family members were assessed for nine traits, including adaptability, anxiety, self insight, and hostility to patient and the hospital staff. Seventy-five percent of the 399 family members assessed were found to have a potential for resourcefulness. Husbands and mothers were more likely to have little or no potential for resourcefulness. Fathers, wives and siblings were more likely to have a marked or moderate potential for resourcefulness.
Parents' Problems, Needs and Characteristics


The families of 125 mental patients who had recently been released from Ohio state hospitals were studied to evaluate the effect of the movement to return the mentally ill to their homes and communities. The author concluded that his sample of relatives would willingly house their ill family member in the home for an extended period of time without rehospitalizing the individual. Although families display little shame or embarrassment about the ill family member, when the former patient's symptoms continue to persist, families demonstrate signs of social and emotional strain. The community mental health movement must monitor the family-patient conditions within the home and must offer institutionalized support and relief for the families of the mentally ill. If family and community concerns do not receive the necessary attention, the author suggests a possible reversal of the trend towards community care and a return to institutionalized care.


Parents of children nearing the end of extensive hearing and speech therapy were interviewed regarding their program experience. On the whole they appeared satisfied with clinical procedures; however, several problem areas emerged in parent-professional-child relationships. These included: (1) the length of time that elapsed between first requesting services and the actual start of therapy; (2) lack of guidelines for which services to choose; (3) not being told how to prepare children for sessions; (4) poorly timed or insensitively handled explanations of findings; (5) poor explanations of illness and parents' roles; and (6) not being informed of progress and the probable length of the rehabilitation program. Professionals are encouraged to address those areas which are applicable.


The author is an educator and the parent of a severely disabled son. She discusses how both parents and siblings cope with their feelings and the stress a disabled child causes within the marital relationship. The book's central themes are the four subjects parents discuss when contemplating their child's disability: professionals, parental unhappiness, the family, and the road to recovery. The author recommends that professionals aid families in the four following ways: (1) provide information about the disability; (2) display respect for the disabled child, his/her parents and the relationship between the parents and the child; (3) offer concrete services to children and their families (therapy, education, advice about architectural adaptations, etc.); and (4) offer emotional support.
Parents' Problems, Needs and Characteristics


This literature review focuses on the stresses families experience and the support factors needed to help them cope with their handicapped children. Stress often appears to increase with the age of the handicapped child, and it is also based on the daily care-giving demands of the child. Other general factors affecting stress are low family income, divorce, separation, and so forth. The father often plays a limited role in these families even when present. Both formal and informal social support networks are important to these families, often more so than professional support, which has been uneven. Families need to be treated as having individual needs that require individual solutions, just as their handicapped children must be seen as unique. Investigators and practitioners are encouraged to continue their focus on the family as a legitimate unit of study and treatment. (Journal abstract).


The author argues that public health intervention is needed to assist potentially one million families of discharged mentally ill individuals and more than 500,000 chronically disabled adults who live in the community with their spouses. The increased strain and responsibility which is known as "family burden" may be relieved by the following: (1) family-oriented rehabilitative and treatment services; (2) home visiting; (3) relatives' groups; and (4) community support systems, including comprehensive physical, mental and social welfare services.


Society sends many negative messages both direct and subtle to parents of handicapped children, and professionals are often not as sensitive as they could be. Thus, parents often feel judged and as if they were living in a "goldfish bowl." The author, who is a professional, encourages parents to band together for mutual support and skills sharing and to bring about societal change.
Parents' Problems, Needs and Characteristics


The families of nine young handicapped children were interviewed and related their experiences in locating and securing aid for their disabled children. The experiences of families upon identifying their child as disabled, searching for aid and support, awaiting their child's assessment and receiving services are detailed. Seven suggestions for action which may be taken by professionals to improve their relations with parents and to improve families' abilities to obtain needed services are offered. Suggestions include a recommendation that professionals be trained to understand the importance of their interpersonal work with families, all service systems should have routine procedures which are activated as soon as a disabled child is identified and professionals should view parent support groups as an available resource for improving relations.


Members of a schizophrenia self-help organization were surveyed to determine the effect of the illness upon the family. Family caregivers reported severe emotional and physical strain, fear of the future, fear of physical danger, constant anxiety and grief over the stranger within the family. Five family needs were identified: (1) a clear knowledge and understanding of the patient's disease and practical management and coping techniques; (2) the kinship of other similarly situated families; (3) temporary or respite care for the patient; (4) crisis services; and (5) alternative housing.


Family caregivers of schizophrenics who were members of a self-help group indicated, in response to a questionnaire, that family members find friends and relatives of significantly greater assistance than therapy in coping with their family member's schizophrenia. The author suggested that professionals fail to acknowledge that the prolonged distress and shock which accompanies a catastrophic physical illness similarly accompanies a diagnosis of schizophrenia. Family members indicated that they need the following services and supports: (1) an understanding of the disease and practical information on coping with the illness; (2) the opportunity to talk with similarly situated individuals; and (3) alternative housing or temporary respite care for the disabled family member.
Parents' Problems, Needs and Characteristics


The author studied 89 family caregivers who assumed the primary responsibility for the care of a schizophrenic family member. These caregivers were members of the Schizophrenia Association of Greater Washington, a self-help organization of family members and former patients. Those studied were predominantly suburban women of above average income and education. Effects of the illness on family life included hardship for siblings, a threat to parents' marriage, disruptions of family members' personal and social life, and burden on specific members of the family. Emotional burdens included stress, anxiety, resentment, grief and depression. The author urges that services be created to minimize family distress. Suggestions include practical management techniques for family members, establishing central information resource centers, and home visiting crisis teams.


Thirty caregivers of mentally ill relatives were studied. The purpose of the study was to identify research questions to assist in developing a better understanding of the ways in which caregivers cope with mental illness. The study attempted to discover what it is which distinguishes those caregivers who cope relatively well with those caregivers who experience great difficulty. Coping was defined as "the problem solving effort made by an individual when the demands he faces are highly relevant to his welfare and in which these demands tax his adaptive resources." Coping requires new behavior. Cognitive skills, emotional mastery and need fulfillment were separately rated. The factors were averaged and one overall coping effectiveness rating was assigned to each caregiver. With respect to emotional mastery ("optimism about the patient's condition") high raters displayed an acceptance of the family member's illness. Those who rated low focused only on the present and viewed it as tumultuous. With respect to cognitive skills ("realism in appraising the patient's illness and prognosis") high raters generally could articulate the management techniques they employed. Low raters articulated few strategies for managing the patient and displayed discouragement about their effectiveness. In the area of need fulfillment ("degree of involvement in family, social, work, and community life"), those rated high in coping effectiveness found time for their personal, recreational, travel and community interests. Less effective copers displayed fewer interests.


Family caregivers of mentally ill persons were studied to determine their needs for mental health services and their perceptions about how well their needs were met. There was little congruence between families' expectancies and what they received in therapy. Recommendations were made for changes in professional practice and for the use of alternative helping systems. (Authors' abstract).
Parents' Problems, Needs and Characteristics


The author is the coordinator of Parents of Adult Mentally Ill of Santa Clara County, CA. She argues that parents should be educated about patients’ rights. Handbooks about patients’ rights which are distributed to patients should also be given to families. Patients should not be transferred from one facility to another or discharged without notifying family members. Families should be given the opportunity to share information about medications previously taken by the patient and possible allergies or side effects experienced by the patient. Procedures such as these will assist families in speaking out on behalf of their children.


The literature on coping is reviewed as it relates to families with a psychiatrically disabled relative. Coping is defined as "the way an individual adapts to threatening situations that require the production of new behaviors." A person develops strategies -- inner- and outer-directed psychological processes -- in order to adapt and deal with different life situations. Crisis theory and stress theory are examined as they relate to coping. The family members' coping needs and coping styles are also reviewed and examined. The basis for this paper is found in skills training approach.


A study of 143 families of schizophrenics in the Washington, D.C. area identified a number of problems experienced by the families, all of whom were middle class. Among others, problems included worry about the ill family member, the need to find appropriate treatments, financial concerns and disruption of the family. Families expressed a need for: (1) recommendations for coping with the ill family member's behavior; (2) greater knowledge of symptoms; (3) financial relief; (4) respite care; and (5) the opportunity to talk to other people who understand the family's situation.


The author argues that schizophrenia is a family affair as the entire family unit is affected when one member is schizophrenic. A study was conducted to determine the problems families experience, the treatments they use and the places they go for help in coping with the stresses of having a schizophrenic family member. 89% of the respondents listed "finding effective treatment" as a major problem. "Disruption of family life" was a problem for over three-fourths of the families as a result of schizophrenia. Charts are included to demonstrate and list the results of the problems cited, the therapies used and the supports most needed.
Parents' Problems, Needs and Characteristics


The authors review empirical studies of the reaction of family members to a relative's mental illness and to the family member's hospitalization. The relationship of the family's attitudes (and particularly their willingness to tolerate deviant behavior) to outcome following discharge is also discussed.


Sixty interviews were conducted with parents of handicapped children in one city. Three main areas of concern were revealed: (1) parents prefer to be told about their child's handicaps as early as possible in a manner which allows for plenty of discussion time; (2) a smoothly running system of services would do much to alleviate stress on often worn out and depressed families; and (3) financial grants which enable families to purchase appliances or phones are more helpful than other services. Thus, since resources are limited, it is advisable to involve families in decision-making processes to ensure best possible allocations.


The author organizes parental responses to a handicapped child around the following four areas of expressed concern: (1) general effects on the parents' coping and emotional capabilities (including social isolation, caretaking responsibilities assumed by siblings, fear of having another child, low self-concept with respect to parenting skills); (2) parental responses to their child's aberrant communicative, cognitive, and learning abilities (including bafflement, frustration, sadness and disappointment); (3) parental responses to their child's aberrant affective, motivational and behavioral characteristics (including detachment and cynical objectivity, inability to interpret the child's feeling, vacillation between strictness and permissiveness); and (4) effects on relationships with professionals (increased guilt and confusion) and the public (including confronting ignorance and explaining inexplicable behavior). The author suggests that an understanding of these responses may serve as guides in approaching families.
Parents' Problems, Needs and Characteristics


Forty families with children who were evaluated for suspected mental retardation were studied to determine whether and to what extent parents changed their expectations when they participated in a brief clinical experience. Social workers interviewed both parents prior to the child's initial clinic visit and encouraged parents to, if necessary, apply pressure to staff members to encourage them to share information regarding their child's condition. The social workers offered to manage the communication process between staff and families where problems arose. Both before and after the clinical experience, parents were asked to estimate their child's present abilities and future accomplishments. The study demonstrated that the brief intervention resulted in the parents' assumption of realistic educational and future employment goals as well as their adoption of action in accord with their newly formulated realistic goals.


The vast majority of parents of mentally retarded children experience an intense and chronic sorrow in response to their child's disability. The sorrow endures throughout the parents' lives. Professionals should cease to expect parents to simply accept their circumstance. Parents will both accept and reject their disabled child. Professionals should also acknowledge the ongoing parental sorrow as a normal reaction. Counselors should recognize that parents will require a lengthy period of time to face their circumstances, acknowledge their feelings and gather their resources together. The counselor's goal should be to enhance parents' levels of comfort in managing their disabled child.


Eight needs of families caring for a schizophrenic relative are identified. Caregiver needs include professional assistance and guidance aimed at preventing the schizophrenic's further deterioration, information about the nature of the illness and the efficacy of available treatments, twenty-four hour crisis intervention and professional disclosure of "confidential" patient/client information. Family therapy methods of treating schizophrenia, including theories founded on the expressed emotion concept, are also reviewed. The author submits that high expressed emotion is not unique to families of schizophrenics.
Parents' Problems, Needs and Characteristics


The relationship between the burden experienced by the families of the mentally ill and social support was explored in a study of 56 parents of schizophrenics. The parents were all members of a self-help support group for the families of the mentally ill. The study demonstrated that parents display a low level of burden when they have dense, small, supportive social networks, spousal involvement with the mentally ill child, and satisfaction with the support received by the parents from the self-help group.


The stages of a family's response to the mental illness of another family member are described. Families generally undergo some or all of the following stages: (1) a beginning uneasiness upon sensing that things are not as they should be; (2) an attempt to gain reassurance that, although there may be a problem, it is neither permanent nor serious; (3) minimization of symptoms or denial of the illness' presence; (4) an expression of criticism and mutual recrimination or displacement of their anger about the illness onto professionals and others; (5) guilt and shame upon acknowledging the mental illness sometimes coupled with a belief that the situation is hopeless which is followed by an attempt to withdraw from any participation in treatment; (6) confusion in family members' perceptions of each other and efforts to work out new ways of relating to each other; and (7) as reality is accepted, the formation of an alliance with therapists. Treatment of the family of a mentally ill individual is enhanced if the therapist understands the stages and can initiate a therapeutic response at the optimum time.


Mental retardation research in the 1950's and 1960's focused on families. In the 1970's, however, the focus shifted to alternative treatment settings. Family research conducted in the 1970's can be grouped into eight areas of study: behavior management, continuum of care, deinstitutionalization effects, demographics, family dynamics and adjustment, institutions, parent attitudes, and siblings. In the 1980's research has shifted back to families with three additional areas added: parenting, life cycles and social support networks. This editorial discusses the family as a multi-leveled support source and suggests the field of social support as a fertile area for future research.
Parents' Problems, Needs and Characteristics


The author, a parent of a disabled son, offers a first person account of her adjustment to her son's disability. She discusses her recognition of her child's problems and her experiences in learning to express her feelings. The author found that feelings of isolation, helplessness, frustration, anger and jealousy are natural. Normalization occurred as she learned to compensate for those facets of the usual parent-child relationship which are missing with a handicapped child.


The father of a retarded child writes of his experiences and his belief that the parents of handicapped children go through a series of stages and ultimately accept and adjust to their child's disability. The author believes that parents' shock, guilt and bitterness remain a part of the parent's emotional lives. Feelings remain unresolved and contradictory.


The authors report the results of a survey which sought to: (1) identify the practical needs and coping strengths of the families of the severely psychiatrically disabled and (2) to identify the perceptions of mental health professionals of family needs and coping strengths. Forty-five percent of the respondents reported overall dissatisfaction with mental health services. Core dissatisfactions rested with individual therapy, medication management, vocational and social rehabilitation. Families expressed a need for professional assistance in the areas of obtaining referrals, treatment coordination, emotional support, and obtaining practical advice and information about the illness. While 64% of the respondents indicated that they were coping well, 35% reported that they were not coping well. Coping strategies, including learning to set limits and learning to distance oneself from uncontrollable behaviors, are enumerated. The survey of professionals disclosed that most professionals believe families are satisfied with the mental health services they receive and that they further believe families are very to moderately contented with the activities of professionals within the mental health system.
Parents' Problems, Needs and Characteristics


Findings are presented from a 1978 survey of 330 parents of developmentally disabled children in Lake County, Illinois regarding their current satisfactions and projected needs. The first section portrays the sample demographics (age, sex, type of disability, yearly family income, area of residence). A section on family support analyzes responses in the following service areas: health care delivery, social service delivery, recreation and leisure, and emotional and informational sources of support. Among results described are that approximately two-thirds of the parents were satisfied with the initial diagnosis and assessment; the relationships of family income to health care services and social services were complex; the younger the disabled child, the more likely parents were to be satisfied with social service professionals; and the greatest informational needs reported were for a parent manual and a referral service. Life course planning is the focus of the final three chapters which analyze findings on schools and developmental programs, residential options, and community acceptance and consumer action. (ERIC abstract).


A random sample of 125 care-giving relatives of mentally ill persons were interviewed in their home to examine the emotional and social costs of caring for their mentally ill family member. Data on how families of the mentally ill cope with their care-giving responsibilities is provided. Three major findings are reported: (1) When "social costs" are redefined to include subjective burdens as well, patients' families have been placed in an emotionally demanding situation; (2) emotional burdens equally affect families of differing races, classes and composition; and (3) coping burdens should be separated into "objective" and "subjective" components.


Schizophrenia can be difficult to live with, and families are often unnecessarily burdened by ignorance, fear and guilt about this disease. This compassionate guide was written by a psychiatrist to provide detailed information with illustrative examples which may help families make important decisions about care for the schizophrenic family member. Subjects covered include: (1) distinguishing schizophrenia from other similar conditions; (2) the progress, causes and history of schizophrenia; (3) how to choose good treatment before and after hospitalization; (4) what role the family can play; (5) how family members can deal with their own difficult feelings about the situation; (6) demographic information about the disease; and (7) ethical, legal and legislative issues. The neglect of schizophrenia by psychiatry and researchers is emphasized. Advocacy and lobbying are urged.
Parents' Problems, Needs and Characteristics


This collection of candid and personal stories from relatives and parents of the disabled is the second edition of a volume first published in 1978. Follow-up articles have been added to many of the original essays, and some new contributions have been included. Though these stories often relate family struggles to locate and obtain proper care, as well as personal pain experienced, they also testify strongly to the richness and joy often found in caring for a disabled child, and the value inherent in living such a life, both for the relatives and the disabled.


Parents of young chronic patients surveyed displayed a low level of satisfaction with the services their children received. Many patients do not even use community services. Of those who do, their families expressed dissatisfaction with the services received. Services include sheltered workshops, vocational rehabilitation services, social rehabilitation services, educational services and day treatment. Families identified social and vocational rehabilitation as the areas most in need of improvement. The authors propose skills training in an educational setting as an alternative to traditional mental health services.


Relatives of the mentally ill describe their experiences in locating a therapist, selecting a halfway house or hospital, selecting an outpatient program, living in the same home with a mentally ill person and organizing family support groups. The appendices include a glossary of mental health terminology, a guide to the involuntary and civil commitment statutes in each state, tables of psychotropic drugs and a list of resources available to serve the mentally ill.


Two groups of mothers -- one with retarded children, the other without -- were surveyed to compare their social behaviors and attitudes regarding mental retardation. Significant differences were found regarding the use and types of babysitters: mothers with the retarded children were three times more likely to use a relative rather than an unrelated neighbor, and to use babysitters no matter what the age of the retarded individual. Mothers with retarded children were twice as likely to work part-time rather than full-time. They also perceived the average community member as having negative attitudes about mental retardation.
Parents’ Problems, Needs and Characteristics


In response to a questionnaire mailing, parents of mentally retarded children and social workers essentially agreed that such parents experience periodic crises during the child’s development, rather than time-bound adjustment. Social workers tended to underestimate the impact on parents of later developmental periods. Clinical implications of the findings, which run counter to the prevalent professional view, are considered. (Authors’ abstract).


One hundred twenty mothers of severely mentally disabled children were interviewed. A primary objective of the study was to determine the child care and housework burdens borne by mothers and the support they received. The study concluded: (1) community care of handicapped children largely rests upon mothers; (2) public services offer little help with the daily care of disabled children; (3) there is minimal social support for the families of the disabled; (4) mothers’ decisions to seek residential placements for their children is related to their expectations and needs for more support rather than to the assistance they receive for housework and child care.


Six needs which families of the mentally ill feel when the ill family member is hospitalized are enumerated. The families’ needs affect their attitudes towards both the patient and the patient’s caretakers. Families: (1) seek a speedy cure for their family member’s illness and must, therefore, be educated with respect to the capabilities and limitations of psychiatry and to the distinction between maintenance therapy and curative agents; (2) desire information about the cause and treatment of the mental illness; and (3) need information about daily management methods. Moreover, professionals: (4) must strive to ensure consistency of care for the mentally ill; (5) must improve their communications with professionals who have previously treated the ill individual and (6) must educate themselves and families about the presence or absence of community resources.
Guidelines and Programs for Parents and Professionals


A self-advocacy cycle consisting of the following four stages is explained: (1) targeting the needs of the family and individual; (2) preparing to meet with professionals to address the identified needs; (3) influencing human services agencies to adopt the advocates' proposed methods of addressing the targeted needs; and (4) follow-up or monitoring efforts to insure that agreements made between professionals and self-advocates are effectuated.


Training to ally with parents and meet some of their needs is rarely given in the professional education of teachers who work with special children. Some parents have been long aware of their children's needs, and some are surprised, but both types would benefit from better parent-teacher interaction, especially in the parent-teacher conference. It is also noted that parents tend to regard teachers more positively than teachers regard parents. This book focuses on parent-teacher encounters, giving information about general school referral and reporting processes and discussing the parent role as perceiver, learner and teacher. An activities outline for a parent program is also provided.


This clearly written guide offers information and support to the families of persons diagnosed as chronically mentally ill. Background information on mental illness, medication, the mental health system and legal issues is provided. The feelings, needs and difficulties family members may experience are discussed. Suggestions as to how the family can be involved with treatment, community action and self-help organizations are offered. Interviews with family members are included.
Despite the many positive gains from increased parental participation in the education of handicapped children brought about by P.L. 94-142, many parents still encounter stigmatization, resistance and indifference from schools concerning their children's education and have given up in frustration. Parent involvement remains, however, important. Parents often have information that is invaluable for teachers, such as food preferences or an understanding of particular behaviors. Also, parent advocacy groups have often been effective politically where teachers or administrators have not. Suggestions are given for effective parent advocacy, and many strategies are given for schools to encourage parental involvement. Possible parental roles in schools include coaches, advisors, consultants, aides and co-teachers. Illustrative examples are given from successful programs in schools around the country.


This booklet is aimed at parents of emotionally disturbed children. The authors offer general information about emotional disorders, a discussion of the types of programs parents should consider for their children, an explanation of different types of therapies, an explanation of the various kinds of mental health professionals and a discussion of the role parents play as their children's primary services coordinator. Suggestions for financial aid, a recommended reading list and the services available to families of emotionally disturbed children in the state of Minnesota are also offered.


The effectiveness of early education programs for handicapped children is related to the strength of the home-school connection. Family members can and should be involved in a variety of roles as participants, partners and policy-makers. To help program planners meet parent needs, suggested activities in five areas are given: providing social and emotional support; facilitating information exchange; encouraging parental participation in the classroom, establishing a parents' club, providing suggested ways to improve child-parent interaction; and developing marketable parents' skills. The process-oriented ATSEM (Acquaint, Teach, Support, Expand, Maintain) Model is presented as a program that actively draws parents in and involves them in the educational process. Worksheets to aid in developing early education programs are provided.
The purpose of this learning module is to make the teacher knowledgeable about the ways in which parents of handicapped children can be usefully and effect­ively involved in the education process. It is also designed to develop some elementary skills in training parents. After a test on selected readings, the students learn how to conduct a survey to determine current attitudes of practitioners toward parental involvement and how to tabulate and analyze the data. Information is presented on parent organizations and programs for the handicapped. Guidelines are given for communicating with parents, parent-teacher conferences, and workshops for parents. Answers to tests are found in the appendix. (ERIC abstract).

This "Instructor's Manual" is designed for those responsible for guiding trainees through module II on "Parent Involvement in the Education of Young Handicapped Children: How Parents Can Help." The responsibilities of the instructor are outlined, and the means for satisfactory completion of the module are clarified. An answer key is given for the pre- and post-assessment tests. (ERIC abstract).

Closer Look (the National Information Center for the Handicapped) is a clearinghouse for information on services to the disabled. Consumers include the parents of disabled children, professionals, parent groups, the adult disabled and students seeking career information. Closer Look has taken the following steps to meet the needs of parents: (1) parents are referred to local parent organizations to obtain emotional support from other parents and information on essential services; (2) special education laws and the necessary steps required for obtaining their statutory rights are explained; and (3) the center offers assistance in forming advocacy coalitions. Additionally, Closer Look has initiated a program to prepare parents as advocates for their children.
Guidelines and Programs for Parents and Professionals


The sixth of seven monographs on early intervention for young (birth to age 3) handicapped children is intended for parents and other family members. Materials which focus on five topics appropriate for parent groups (overcoming communication barriers, rights and responsibility, self concept and their children, toy construction for learning, and professionals' roles) are described. A series of three annotated bibliographies comprises the remainder of the book. Topics addressed are young children (child development and learning, activities and toys, self concept, health and safety, behavior); handicapped children (biographies, legal issues, general and specific handicaps); and activities to understand feelings and handicaps. Bibliography entries include information on title, author, topic, date, and publisher along with a brief description. (ERIC abstract).


Two participatory workshops designed by Professional-Parent Consultants are described. The workshops are designed to educate professionals with respect to the demands and frustrations experienced by the parents of handicapped children. "Major factors that were considered in developing these workshop presentations were (1) how a handicapped child affects a previously 'normal' family unit, (2) how the professional's perception of parents and subsequent actions are frequently based on the 'reputation' of the parent or on shallow and minimal information derived from first impressions, (3) the lack of understanding by professionals of 'realism' and 'acceptance' of hope." Participants in "The Other Shoe" workshop act as the parents of disabled children and are introduced to the financial and other crucial concerns experienced by the parents of the handicapped. Workshop attendants have demonstrated positive behavior and attitudinal changes following their participation in the workshops.

Hatfield, A.B. (n.d.). Coping with mental illness in the family: A family guide. Maryland Department of Health and Mental Hygiene, Mental Hygiene Administration and National Alliance for the Mentally Ill.

The family can be a lifeline of support to a mentally ill person, especially at times when community resources may not be working. Yet living with mental illness is often a great strain on families. This clearly written manual addresses family concerns and offers information and guidelines for effectively providing support for all family members. Topics covered include the effect of mental illness on a family, information on chronic illness and its treatment, and suggestions for creating a low-stress environment. The author also suggests behavior management techniques for disturbing or aggressive behaviors and directions for further development and rehabilitation of mentally ill persons.
Guidelines and Programs for Parents and Professionals


The resource guide lists approximately 700 print materials and audiovisual programs (1970-1979) designed to support training efforts for parents of handicapped children. Intended for parent training, for direct parent use, and/or for professional training, the materials are organized into four categories (sample subtopics in parentheses): impact on families, available support services, resource and equipment, and characteristics, diagnosis, and education of 10 exceptionalities; materials to help parents foster their child's development at home; information on parent/school relationships (parents' rights and responsibilities, development of parent involvement program); and resources for planning for the future (postschool services). Each citation includes title, author, date, price, format information, and a brief description. A final section lists organizations providing services to families with handicapped children. (ERIC abstract).


TOPS (Training Outreach Prevention School) parent training and support groups are designed to assist parents of emotionally disturbed children by providing concrete support for better understanding and training in coping skills for behavior management, communication and assertiveness. This second report is a guide to the philosophy and practicalities of organizing parent groups and motivating parent participation. Training techniques and a workshop module are given, along with sample behavior tally and record sheets. This appendix includes a paper entitled "The ABC's of Behavior Modification."


Planning and implementing community support services for seriously emotionally disturbed youngsters can be a complex task for families. This workbook provides focus for goal clarification and identification of community resources, suggests means of coordination and tracking of services and participants, and discusses mediation and conflict resolution with providers and agencies. A five step process of service development is presented, and worksheets and sample forms and letters are provided.
Guidelines and Programs for Parents and Professionals


Parent power is an underexercised but potentially valuable and effective means to obtain appropriate services for exceptional children. For many reasons parents are often disregarded in school decisions. Thus it is important that basic assertiveness skills be learned. Practice worksheets are given for parents to develop their desired communications clearly, and three levels of assertive statements about children's needs are modeled.


The American Academy of Pediatrics developed a sixteen hour inservice program for use in training physicians who serve disabled children and their families. The project is designed to affect physicians' (1) attitudes towards disabled children and their families; (2) substantive knowledge about disabled children; (3) clinical skills in working with the disabled; and (4) involvement with the school system. The training curriculum has four modules which focus, respectively, on the child, the family, the educational system and the community. The child module seeks to provide information on screening, identifying and diagnosing specific disabilities as well as reviewing available therapies. The family module offers information on how to inform parents of their child's handicap and the impact of the disability on the family. The educational module introduces physicians to services offered to handicapped children in the educational system and to relevant legislation affecting disabled children within the school environment. The community module is designed to heighten physicians' awareness of the obstacles and problems disabled children face in the community and to educate doctors with respect to their role in directing families toward available community resources.


A group of preschool teachers were randomly assigned to a microcounseling group and to a didactic lecture control group. Each group participated in training sessions designed to teach parent-teacher learning communication skills. Microcounseling group members viewed a parent-teacher interaction videotape and then participated in role-playing and discussion activities. The didactic lecture group members heard an informational lecture followed by discussion. Microcounseling group members demonstrably increased their learning of specified responses to initial contacts with difficult parents. Inservice training experiences for teachers in communication skills should be designed accordingly.
Guidelines and Programs for Parents and Professionals


Both educators and parents need to work together to develop better individualized education programs for handicapped children. This workshop guide is designed to assist facilitators who present in-service trainings to educators aimed at improving parent-teacher collaboration. A complete twelve-hour five-module workshop with suggested activities and participant material is presented. The materials address such areas as teachers' negative experiences working with parents, gaining full information about the student, improving communication, developing timing and settings, and implementation and evaluation of plans. Appendices include the due process rights afforded to parents under P.L. 94-142, a parental survey form and a parents' guide to information gathering.


This clear and detailed guide for advocacy is addressed to everyone who advocates for individuals, families or groups. Topics covered include: selecting issues, planning and study of goals and strategy, intervention methods and a discussion of the process of initiating, passing, implementing and monitoring new legislation.


Families of persons diagnosed as chronically mentally ill often feel isolated and may not have access to the parent advocacy movement. This book was written by the mother of a chronic schizophrenic child who is also a professional social worker. It is intended as an information guide and primary support for families struggling with the onus of guilt for causing the condition. Discarding the double-bind theory is recommended. The deficiencies of the mental health system in which the author works and the poor protection provided by the legal system for schizophrenics are discussed. Information is given about choosing professionals, treatment modes and coping with deinstitutionalization.

Families are increasingly being recognized as important resources and are included in the treatment of schizophrenia and major affective disorders. Often professionals are asked to recommend books on the subject. Here is a clearly written guide to 28 books published since 1950, including first person accounts and guides written by and for families and professionals. Many are already well known, and some are suggested to better inform professionals. Besides highlighting outstanding features of the books, the author also indicates where information might be misleading to families or may be outdated. Many books selected emphasize the emotional impact of mental illness, and several deal with deleterious effects of separation from family.
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