#### DOCUMENT RESUME

ED 361 937 EC 302 404

AUTHOR Adelman, Sally; And Others

TITLE Collaboration between Professionals and Families of

Children with Serious Emotional Disorders: Annotated

Bibliography.

INSTITUTION Portland State Univ., OR. Research and Training

Center on Family Support and Children's Mental

Health.

PUB DATE Jul 92

NOTE 93p.; A product of the Family as Allies Project. PUB TYPE

Reference Materials - Bibliographies (131) --

Information Analyses (070)

EDRS PRICE MF01/PC04 Plus Postage.

DESCRIPTORS \*Advocacy; Annotated Bibliographies; Early

Intervention; Educational Cooperation; Elementary Secondary Education; \*Emotional Disturbances; \*Parent School Relationship; \*Parent Teacher Cooperation;

Special Education

**IDENTIFIERS** \*Empowerment

### **ABSTRACT**

This annotated bibliography lists 136 entries, divided among 9 chapters, on the collaboration between professionals and families of children with emotional disorders. Entries are listed alphabetically by author within each chapter and date from 1974 through 1993. The first chapter, "Need for Collaboration," briefly surveys the literature regarding families' experiences in working with professionals and establishes the need for a different kind of family-professional relationship. The next three chapters ("Persons with Severe and Persistent Mental Illness," "Children with Serious Emotional Disorders," and "Children with Other Disabilities") review the family-professional collaboration literature as it applies to three specific populations. Chapters 6 and 7 consider the literature on early intervention and general educational settings for children with emotional disorders. Available literature on how families and professionals can collaborate as advocates for children with mental disorders is reviewed in Chapter 8. A final chapter on empowerment lists materials stressing the principle of participant ownership of the processes of advocacy, intervention, and rehabilitation. (PB)

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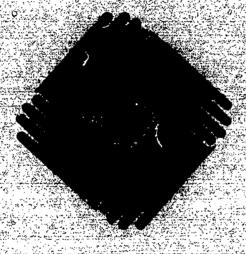
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## ANNOTATED HIB LOGGAPHY

## COLLABORATION BETWEEN PROFESSIONALS AND FAMILIES OF

### CHILDREN WITH SERIOUS EMOTIONAL DISORDERS



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July 1992



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### Introduction

The concept of family-professional collaboration on behalf of children with emotional disorders has gained increasing attention over the past few years. This perspective is based upon the fact that families are key service providers to their children and an invaluable resource to professionats designing interventions on their behalf.

Evidence of the growing interest in family-professional collaboration may be found in numerous writings that have appeared over the past five years. An annotated bibliography published by the Families as Allies Project of the Research and Training Center on Family Support and Children's Mental Health in May 1986 had one chapter devoted to the general topic of Parent-Professional Relationships. This current bibliography, which is devoted exclusively to collaboration between families and professionals, contains 136 entries of which over 80 percent have appeared since the publication of the 1986 bibliography. The number and specificity of the writings available for inclusion in this bibliography should be encouraging to both families and professionals interested in children's mental health.

Though this bibliography is a product of the Research and Training Center on Family Support and Children's Mental Health, the citations include works well beyond the field of children's mental health. Much of the basic development and subsequent advancements to the notion of family-professional collaboration have come from other fields, specifically education and adult mental health; therefore some readings from other fields which were judged to be important are included within this work.

Given the number of writings included in this bibliography, we have attempted to categorize them by chapters to provide organization and to assist readers in finding relevant material. As in any such attempt, there are severe limitations to neat categorization. There are many writings which could easily fit in more than one chapter. We hope that our attempt at organization facilitates rather than hinders the use of this document.

The first chapter, Need for Collaboration, briefly surveys the literature regarding families' experiences in working with professionals on behalf of their children with severe emotional disorders and establishes the need for a different type of family-professional relationship. Chapter Two, Recommendations for Collaboration, reviews the literature containing suggestions or guidelines to establishing collaborative relationships. The next three chapters (Persons with Severe and Persistent Mental Illness, Children with Serious Emotional Disorders, and Children with Other Disabilities) review the family-professional collaboration literature as it applies to three specific populations. Populations other than children with serious emotional disorders are included because this literature can be very informative to practitioners and families interested in collaboration. Chapters Six and Seven, Early Intervention a id Educational System, consider the literature addressing collaboration in two key settings for children with emotional disorders. Chapter Eight, Advocacy, reviews the fairly limited writings concerning how families and professionals might collaborate in advocating for children's mental health issues. Finally, Chapter Nine is entitled Empowerment. While empowerment is the primary focus of this final chapter, it is important to recognize that family empowerment is an essential part of family-professional collaboration and is a theme in many of the entries included throughout the bibliography.

While the authors of this bibliography and the entire Research and Training Center staff are committed to the use of "people first" language, we did not feel it was appropriate to change the writing style of the original authors of a publication. For example, if the



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original author consistently used the term "schizophrenic" within her/his work, we did not change this to "person with schizophrenic illness" in the preparation of the abstract.

Finally, despite the number of entries within this bibliography, it is disappointing to note the paucity of research in the area of family-professional collaboration. The few studies that have been conducted are included. The existence of this bibliography is evidence of the increased interest in and growing acceptance of collaboration. Given the importance of this concept to the children, families and professionals involved in the field of children's mental health, it is clearly time to take a more rigorous scientific look at the process and outcomes of collaboration. What is collaboration? How does collaboration work? Does it work in all family-professional relationships? What are the results of a good collaborative relationship? These are just a few of the questions that need to be asked and which will lead to a better understanding of family-professional relationships.



# NEED FOR COLLABORATION



Cournoyer, D.E. & Johnson, H.C. (1991). Measuring parents' perceptions of mental health professionals. Research on Social Work Practice, 1(4), 399-415.

The authors note that parent resistance and attrition rates in children's mental health services may be related to parents' perceptions of professional behavior. The impetus of this research is that the views of parents play a vital role in professional work with children.

A scale was developed to measure parents' perceptions of behaviors of the mental health professionals who serve them. The Helping Behaviors Checklist was designed using principles from professional codes of ethics. Employing a panel of experts to test the content validity of the scale and a field test of parents to test reliability, the research found the scale to be a fit tool for measuring parent perceptions of professional behavior.

Gartner, A. (1988). Parents, no longer excluded, just ignored: Some ways to do it nicely. Exceptional Parent, 18(1), 40-41.

The author states that although parent involvement is identified as a top priority of special education and mental health professionals, this priority appears to be nothing more than rhetoric. Professionals profess the importance of parent involvement yet allow parents very little involvement or equality in the process of providing services to their children. Examples are given of the ways in which professionals are condescending or patronizing, rather than respectful, when interacting with parents of children with disabilities.

Iris, M.A. (1988). The parent/professional relationship: Complex connections, intricate bonds. Family Resource Coalition Report, 7(2), 9.

A parent of two children with disabilities discusses her experiences with medical and social service systems. The importance of the family unit is stressed as well as the individual needs of a child with a disability. The author feels that the parent/professional relationship involves difficult and complex interactions that can be threatened by feelings of blame, dependance, and a child's failure to progress. There are few professionals who know how to work side-by-side with parents in developing a comprehensive, long term plan for a child. Professionals who seem to truly care about the welfare of the child and the family and are able to provide services promised through a contractual agreement will achieve successful working relationships with families.

Knoli, J. & Bedford, S. (1989). Respite services: A national survey of parents' experience. Exceptional Parent, 19(4), 34-37.

The authors report on information obtained from a "respite survey" responded to by more

Need for Collaboration

than 2,800 subscribers to Exceptional Parent. A wide variation in state-to-state use of respite is seen as indicating major differences in availability and accessibility of services. Whereas the public sector seems to regard respite as an extraordinary resource, families regard it as a necessity of daily life. The authors suggest the need for expansion of respite and its integration into a comprehensive system of day care. In interviews of families conducted at the same time as the surveys, many families conducted "family support" with "respite," indicating limited exposure to the broader approach to family support is currently advocated. Lack of substantive consumer involvement in the design, management and evaluation of support services lead the authors to conclude that little evidence exists showing change in traditional professional-client relationships to promote values of consumer empowerment and control.

Lipsky, D.K. (1985). A parental perspective on stress and coping. American Journal of Orthopsychiatry, 55(4), 614-617.

The author examines the basis of professional prejudice toward families of children with emotional and physical disabilities. Professionals often believe that parents are too emotional or naive to participate effectively in assessment, treatment planning, and intervention. Some of the major biases against families are identified in professional literature. Due to small sample sizes, research results on family stress levels were done on small samples and cannot be generalized to the overall population of families. Second, many studies were conducted before new legislation regarding children's rights was implemented. Finally, research often focuses on the negative aspects of parenting a child with a disability and does not correctly identify the family's needs and strengths. Little attention is given to the family's resilience and ability to function well in spite of numerous stressors. The current manner of conducting research focuses on the family weaknesses and reinforces the professional's role as an authority. This does not promote emotional growth or collaboration between professionals and family members. The parent's primary role is to care for his or her child, and it is essential that parents are included as a part of the treatment team and dealt with as people who have a lot to contribute to decisions and interventions.

Malekoff, A., Johnson, H. & Klappersack, B. (1991). Parent-professional collaboration on behalf of children with learning disabilities. Families in Society: The Journal of Contemporary Human Services, 72(7), 416-424.

The authors report on a project designed to increase parent and professional collaboration on behalf of children with learning disabilities. The Learning Disabilities Project employed an "action-research approach" to bring together parents, students, and professionals to attain mutual discovery and action.

The action research process involves needs assessment, program development, coalition building, and replication. Small group development plays a key role in this process as the groups go through well-defined phases named after the predominant action in each phase: irritate, contemplate, investigate, elevate, stimulate, and activate.

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Need for Collaboration

The authors cite the differences in perception of needs in developing quality programs between parents and professionals as evidence of the need for projects similar to the Learning Disabilities Project. Parents interviewed noted the need for more extensive evaluations for children and increased parent involvement while professionals expressed general satisfaction with existing programs but the need for increased professional staff. Bringing these groups together, the project fostered discussion, consciousness raising, and action.

Moroney, R.M. (1986). The professional response: The caregiving function. Shared responsibility: Families and social policy (pp. 121-142). New York: Aldine De Gruyter.

The author suggests that even when social services are often provided to families with a member with disabilities their primary need is support. The question is raised whether increased resources would filter down to support families or if the attitudes of people responsible for providing service would limit this use of resources.

An extensive content analysis of literature published during the past twenty years was performed for populations such as people with mental illnesses, mental retardation, and physical disabilities. Each publication was evaluated in terms of four conceptual views: (1) families as part of the problem; (2) families as resources to individuals; (3) families as team members; and (4) families needing resources. The pattern of distribution was not consistent across the population categories. In the categories of mental retardation and physically disabled adults, the emphasis was on viewing families as a part of the team; however in the categories of mental illness and physically disabled children, families were primarily perceived as a part of the problem. This variation was attributed to dissimilar theoretical underpinnings in the areas of disabling conditions: development (retardation), psychiatric (mental illness), and medical (physical disability). The authors conclude that without a change in professional attitudes toward families, additional resources will not necessarily result in more support for families caring for members with disabilities.

Wasow, M. & Wikler, L. (1983). Reflections on professionals' attitudes toward the severely mentally retarded and the chronically mentally ill: Implications for parents. Family Therapy, 10(3), 299-307.

The parents of children with Severe Mental Retardation (SMR) or Chronic Schizophrenia (CS) are highly involved with professionals, yet their levels of satisfaction with services varies greatly. The authors' research suggests that the discrepancies are related to attitudes held by professionals concerning the etiology of SMR and CS. A review of literature on families of children with disabilities suggests that professionals view the families of individuals with SMR in positive terms and view families as part of the treatment team. In contrast, the families of individuals with CS are most often viewed in negative terms, such that the family is deemed part of the problem. For many years schizophrenia was considered to be caused and aggravated by the family and its failure to consistently meet the emotional needs of the schizophrenic. Recent research has shown that schizophrenia is

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Need for Collaboration

organically caused and is not a failure on the part of the family. Unfortunately, many professionals retain attitudes and beliefs that the family is a causal factor in chronic mental illness, and this belief has negative implications for their work with families and the child with a mental illness. The social environment of individuals with CS can inhibit or enhance their level of functioning, and the attitudes of professionals who work with these individuals contributes highly to the social environment. Negative attitudes can affect a parent's self-concept and their quality of parenting, which in turn has an impact upon the child.



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# RECOMMENDATIONS FOR COLLABORATION

Bailey, D.B., Jr. (1987). Collaborative goal-setting with families: Resolving differences in values and priorities for services. *Topics in Early Childhood Special Education*, 7(2), 59-71.

"The premise of this paper is that a fundamental problem is the inability of professionals and parents to engage in collaborative goal-setting. This conflict will invariably limit intervention success if the interventionist attempts to impose a set of values or goals that are not acceptable or important to an individual family." Disagreement may occur either over goals or over methods to achieve a goal and may be fueled by disagreement over priorities or over values.

The authors view collaborative goal-setting as a means of empowering parents and increasing their investment in the intervention process. Five basic skills are delineated as requirements for effective collaborative goal-setting: (1) viewing families from a systems perspective; (2) assessing family needs systemically; (3) using effective communication techniques; (4) negotiating priorities and values; and (5) acting in a case management capacity in obtaining resources. In negotiating it must be recognized that differences in values are inevitable and that a mutually acceptable solution will necessitate consideration of a range of alternatives. Through the process of negotiation an atmosphere is created between families and professionals of mutual respect and understanding of each other's perspective.

Cegelka, P. & Mendoza, J. (1988). Family and professional collaboration. (unpublished).

The authors argue that equal partnership is nowhere close to being achieved in the development of education and treatment programs for young children with disabilities despite the advantages of and legal mandate for family and professional collaboration. Barriers to developing partnership are categorized as: (1) psychological/attitudinal; (2) cultural/demographic; and (3) structural/organizational. Parents & Professionals Advocating for Collaborative Training (P-PACT), a training program designed to facilitate parent-professional and interagency collaboration, is described. A conceptual model of the P-PACT program is presented detailing the developmental steps this program builds upon. Separate but parallel developmental steps are utilized for parents and professionals which then merge for the development of collaborative leadership skills. Recommendations are included for action required at state and local levels to develop comprehensive training programs.

Dunst, C.J. (1987, August). The individualized family service plan: Assessing and meeting family needs. Paper presented at the Second Annual Williamsburg Early Intervention Institute, Williamsburg, Virginia.

The authors describe four comprehensive principles to be used as guidelines for meeting the needs of families in a manner that increases the likelihood of positive effects on child, parent, and family functioning. In summary, the principles are to: (1) base interventions on family identified needs, aspirations, and priorities; (2) use the family's existing functioning

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style (strengths) as a basis for promoting their ability to mobilize resources; (3) emphasize strengthening the family's personal social network, and encourage the use of untapped sources of informal aid and assistance; and (4) promote the family's ability and skill base in accessing community resources.

Dunst, C.J., Johanson, C., Rounds, T., Trivette, C.M. & Hamby, D. (in press). Characteristics of parent-professional partnerships. In S.L. Christenson & J.C. Conoley (Eds.), *Home-school collaboration: Building a fundamental educational resource.* Washington, D.C.: National Association of School Psychologists.

In this chapter the authors present definitions of parent-professional partnerships found in the literature and discuss the relationship between parent-professional partnerships, effective helping, and empowerment. Literature is cited in corroboration of the greater efficacy of an active helping style that is competency enhancing over a style in which help seekers passively respond to advice from help-givers. Partnerships are described as enabling experiences that create competency enhancing opportunities with empowering consequences.

A survey on parent-professional relationships was utilized to obtain information regarding characteristics of partnerships. Trust, mutual respect, open communication, honesty, active listening, openness, flexibility, caring, understanding, shared responsibility, full disclosure of information, information sharing, acceptance, mutual support, and commitment to the relationship were some of the most highly ranked characteristics. These characteristics are organized by the authors into sets of behavioral states and traits. Case studies are presented to illustrate how the partnership characteristics produce competency enhancing effects for families.

A model is developed by the authors that postulates the growth of partnership between parents and professionals as a function of both interactive time between the parties involved and the display of behavioral states and traits characteristic of partnerships. It is suggested that the list of characteristics found to be major elements of partnership may be used as a "checklist" for professionals in assessing their practice and for parents in assessing their relationships with professionals.

Education Transition Center. (1988). Building bridges: Technical report on strategies for parent-professional collaboration training for transition. Sacramento, CA: Education Transition Center, California State Department of Education.

A study based on telephone surveys with 36 programs performing parent-professional collaborative training for transition programs is presented. The transitions involved in these programs were primarily the transition from school to work or community living; however, some programs considered transition in a more comprehensive sense (birth through adult). The following essential strategies for effective training were derived from the analysis of the survey data and are recommended for inclusion in training programs for parent-professional collaboration: (1) representatives from each group of people to be trained should be included on the planning team; (2) the training should be individualized

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to fit the needs of participants by conducting a needs assessment prior to the training and utilizing this for planning purposes; (3) in reaching under-represented populations, representatives of each group should be included in recruitment, planning, and implementation; and (4) one-to-one contact is more effective than workshops for under-represented populations and needs assessment is critical. Change in participants will be positively affected by bringing participants beyond an awareness level to an implementation level through follow-up, establishment of support systems, or a series of trainings from awareness to implementation. The design of workshops should encourage small group information exchange and active audience participation and should demonstrate a positive attitude toward parent participation. Follow-up activities such as support groups, newsletters, and further trainings are essential to ensure continued parent involvement and reinforce training goals. Any materials provided need to be appropriate for the participants. An advisory board with a diverse membership representing the participants may be effective in advising, policy making, and coordinating roles. A grant or local financial assistance may be useful in providing trainings to applicable populations. Both professionals and parents need to be sensitized to each other's frustrations and concerns.

Feldman, R. (1979). Collaborative consultation: A process for joint professional-consumer development of primary prevention programs. *Journal of Community Psychology*, 7(1), 118-128.

The author describes the process of collaborative consultation in which professionals and nonprofessional consumers work together to develop prevention programs in the community. The collaborative consultation process allows the consumers' opinions and needs to mesh with the theory and research generated by the professional community. The two parties are able to solicit information from each other, as well as recognize the validity and/or limitations of their own perspectives. The mental health professional as a collaborator may serve four functions for a group: support group member, planning specialist, information broker, and spokesperson for the professionals' viewpoint. The process of collaboration is described as well as guidelines for teaching professionals and approaches for extending and evaluating the collaborative consultation process.

Friesen, B.J. & Koroloff, N.M. (1990). Family-centered services: Implications for mental health administration and research. *Journal of Mental Health Administration*, 17(1), 13-25.

"This article examines the shifts in policy and administrative practice that are needed in order to move toward a family-centered system of care." The authors describe four barriers to a family-centered system of care: (1) the tendency to focus on the child as the unit of service rather than the family; (2) the primary emphasis on mental health services to the exclusion of a broader range of services; (3) the tendency to focus on formal support and

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ignore informal support networks; and (4) a failure to recognize and utilize the strengths of family members.

There is a need for proactive administrative support to enhance the responsiveness of programs to children and their families and to promote the philosophy of parent-professional partnership. Programmatic and fiscal flexibility is necessary to achieve an approach that begins with the needs of children and families and develops a comprehensive service plan based on these needs rather than beginning with services available and assessing the appropriateness of children and families for these services. Shifting from a staff-dominated case planning process to one open to family participation will require administrative support of individual clinicians as well as programmatic changes. Administrative support for the participation of family members in task forces, planning committees, advisory committees, boards of directors, and as evaluators of services must involve creation of opportunities, provision of information and training, and provision of concrete support services, such as child care, transportation assistance and reimbursement for expenses.

New voles and skills for administrators that are required to develop more family-centered services include: modeling of partnerships with family members; negotiation skills as conflict develops over differences in goals; and working with family members in advocacy activities.

Friesen, B.J., Griesbach, J., Jacobs, J.H., Katz-Leavy, J. & Olson, D. (1988). Improving services for families. *Children Today*, 17(4), 18-22.

"This article describes how parents and professionals are working together to ensure that goals related to 'family support' are translated into necessary policies, programs, and services within the system of care for children and youth with serious emotional disorders." For many years, children who had physical or emotional disorders or needs for continuous supervision were removed from their homes to receive care and treatment. Parents tended to be uninvolved in the treatment process due to assumptions that they were unable to understand or manage tasks related to treatment or because the parents were seen as causal factors in the child's disorder. Today a shift away from institutional care to that of home-based care has fueled the support for families to be highly involved in the planning and implementation of interventions for their children. The two key concepts utilized in improving services are "family-centered care" and "family support." Family-centered care includes services designed to be responsive to the needs of the whole family as well as the child. Family support services help families acquire the support they need to cope with the extra stresses that accompany caring for a child with disabilities. Current proposals for community and state-wide programs emphasize self-determination, family control, full parental participation, and provision of services within the child's own home. Family support services focus on three developmental stages of need: the crisis phase; the need for information and education; and the desire and readiness for skill development. Families who pass through these phases may then focus on tasks such as helping develop services or engaging in advocacy. A detailed description of the Wisconsin Family Ties program is provided to demonstrate the steps communities and states must take to improve and expand services to children and families.

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Guerney, L.F. (1991). Parents as partners in treating behavior problems in early childhood settings. Topics in Early Childhood Special Education, 11(2), 74-90.

The author describes a therapeutic program referred to as filial therapy or child relationship enhancement family therapy (CREFT), developed from the principles of child-centered play therapy. This method of play therapy is generic rather than problem directed in that it is aimed at promoting self-esteem by encouraging the child to play out underlying feelings in a safe atmosphere with an accepting adult. In the CREFT program parents are trained in child-centered play therapy during a weekly group involving parents and siblings as well as the child identified with behavior problems. The four stages of the training include: instruction; practice; home sessions; and generalization. The author describes this program as empowering to parents in that it teaches parents new skills to facilitate their child's behavioral improvement. In its educational perspective the CREFT program promotes the positive potential for growth rather than the pathology of the parent-child relationship.

Jeppson, E.S. (1988). Parents take priority in family-centered care. Family Resource Coalition Report, 7(2), 1-2.

The author identifies eight key components of family-centered care for children with disabilities or special health care needs. The principles discussed are applicable to all settings: early intervention, mental health, education, social service, and child health care. The primary component of family-centered care is the recognition that families are a constant force in children's lives while service systems and professionals are transitory participants. In working with families it is important that professionals work to support the family's care-giving role rather than displace it. Other elements of family-centered care are: recognizing family strengths, sharing complete information, facilitating parent/professional collaboration at all levels of care, encouraging parent-to-parent support, and implementing programs that provide emotional and financial support to families.

Mittler, P. & McConachie, H. (1983). Parents, professionals and mentally handicapped people: Approaches to partnership. Cambridge, MA: Brookline Books.

This book is based on a seminar sponsored by the Bishop Bekkers Foundation in Utrecht and held at the University of Manchester in 1981. The theme of the seminar was "Approaches to Parental Involvement." In attendance were both parents and professionals from each of nine European countries.

The first chapter provides definitions and a rationale for partnership between parents and professionals and examines the realization of partnership at various developmental stages in a child's life. The next two chapters, written by parents in leadership positions of voluntary organizations, explore parents' needs and ways in which parents have supported each other. The four chapters following present specific programmatic examples of approaches to partnership in the early years of childhood. Partnerships between parents

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and teachers of school age children are the focus of the next three chapters. The following two chapters highlight the period of adolescence and young adulthood, with its emphasis on separation and sexuality and the need for new dimensions in the relationships between parents and professionals. In the last section of the book, the current situation in each of the countries in attendance is summarized and possibilities for progress are presented.

Smith, M.K. & Ford, J. (1986). Client involvement: Practical advice for professionals. Psychosocial Rehabilitation Journal, 9(3), 25-34.

Client involvement in the mental health system can be beneficial to both clients/consumers and mental health professionals, yet the realization of full client involvement is not a simple task. The authors review literature concerning the relationships between clients and professionals and offer practical advice to mental health professionals who have an interest and commitment to collaborating with their clients. The involvement of clients can encourage personal empowerment, foster the growth of self-help groups, and help agencies reach their goal of psychosocial rehabilitation. Some additional benefits include clients' increased self-confidence, self-responsibility, coping mechanisms, and organizational skills. The recommendations for professionals who wish to foster client involvement include: have a clearly defined plan with a listing of tasks that clients may perform; ensure that all parties involved understand and mutually agree upon goals; an awareness of personal prejudices and attitudes; acknowledging the client's contribution; and cultivating agency support. The participation of consumers of mental health services enhances the responsiveness of agencies to people's needs by helping to voice and clarify the concerns of clients/consumers.

Ulrey, G., Hudler, M., Marshall, R., Wuori, D. & Cranston, C. (1987). A community model for physician, educator, and parent collaboration for management of children with developmental and behavioral disorders. Clinical Pediatrics, 26(5), 235-239.

"The authors describe a model for physician, educator, and parent collaboration in the management of children with developmental and behavioral disorders. The results of implementing the model with 256 professionals and parents of children with developmental disabilities are described and discussed." This collaboration model was developed by the Special Education Resource Network (SERN) of California, in conjunction with local physicians and parents. The model was implemented through training groups for parents and professionals and run by a core training team comprised of a physician, an educator, and a parent. The training team guides the group through a collaborative decision-making process. The group identifies barriers to collaboration as well as solutions to the barriers and they discuss action planning, implementation of the solutions, and follow up support. The primary method of improving collaboration is a guided discussion that elicits the perspectives of physicians, educators, and parents, and then focuses on mutual concerns, exchange of knowledge, and development of support between participants. Combined data from 25 training sessions highlighted the following barriers to collaboration: problems with the interdisciplinary process (25%), lack of appropriate training (15%), role expectations of

Recommendations for Collaboration



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the professional (13%), and difficulty in involving the parents (11%). Obstacles to communication were the most frequently identified concerns across all training sessions. Preliminary data on the effects of the SERN model on participants showed strong positive evaluation of the usefulness of the knowledge and the degree of training obtained through the program.



# PERSONS WITH A SEVERE AND PERSISTENT MENTAL ILLNESS

Bernheim, K.F. (1990). Family-provider relationships: Charting a new course. In H.P. Lefley & D.L. Johnson (Eds.), Families as allies in treatment of the mentally ill: New directions for mental health professionals (pp. 99-114). Washington, DC: American Psychiatric Press.

The focus of this chapter is to create a description of the ideal family-provider relationship. Open and ongoing communication between professionals and families, mutual respect, and a reasonably equal balance of power are characteristics of an ideal family-provider relationship. Families' rights to disagree with professional recommendations without being branded as "resistant" is emphasized.

Professionals can offer families education about symptoms, causes, treatment and prognosis of their relative's illness; detailed information about medication; and help in developing a style of communication in line with their impaired relative's cognitive deficits. Problem solving, behavior management, and stress management skills are other areas of potentially valuable intervention. Because families have unique needs and desires, individualized plans based on an assessment of family strengths and interests are required. Most important is offering families a truly collaborative role in determining treatment strategies.

Families can offer professionals information on specific signs and symptoms indicative of relapse; knowledge of their relative's strengths and interests; and information on situations perceived as stressful by their relative. Family members are in an ideal position to help monitor their relative's response to medication, to encourage socialization both within and outside the family, and to educate and encourage their relative about the need for medication and attendance at rehabilitative programs.

Barriers to effective collaboration include outmoded ideologies that promote family blame, power inequities embedded in the medical model, and interpretation of legal restrictions governing confidentiality.

Bernheim, K.F. (1990). Principles of professional and family collaboration. Hospital and Community Psychiatry, 41(12), 1353-1355.

Although widely advocated in principle, the author questions the degree to which genuine collaboration with families is found in treatment of individuals with mental illness. Eight principles are presented as necessary components of a comprehensive approach to family involvement. The first principle establishes relatives as empowered members of the caregiving network with unique knowledge and expertise regarding the patient. Implied in this principle is both mutual respect and mutual decision-making. The second principle involves orienting the family adequately to the complexities of the mental health system to promote understanding of the role and function of each particular agency and service provider. Providing multiple channels of communication, both formal and informal, constitutes the third principle, including such mechanisms as phone calls, a newsletter, a family grievance procedure, a family advisory group, and social gatherings. The fourth principle utilizes the framework of coping and adaptation, focusing services on decreasing the family's stress level. A combination of services including emotional support, information, education, advice, skills training, crisis intervention, respite care, and case management is suggested. Individualized service plans tailored to the unique needs of each family are the focus of principle five, while principle six emphasizes flexibility in response

Persons with a Severe and Persistent Mental Illness



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to changing needs as well as consequent review and update of the service plans. Principle seven proposes involvement of the family in advocacy efforts and systemic planning as a way of meeting relatives' desires to be useful and as excellent sources of consumer information. The final principle stresses an ongoing commitment to training and consultation of staff, particularly during the transition from using theories of family pathogenesis to trying the newer models of collaboration.

Bernheim, K.F. (1989). Psychologists and families of the severely mentally ill: The role of family consultation. *American Psychologist*, 44(3), 561-564.

Families now play an integral role in caretaking for a relative with a severe mental illness. Among the family's tasks are: creating an environment that balances the needs of the ill and well family members; finding and accessing services; learning to cope with a relative's residual symptoms of illness; learning to recognize symptoms of relapse; coping with family conflict; and finding ways to resolve negative feelings. Surveys have indicated that a high percentage of parents report dissatisfaction with the help they receive from mental health professionals. The major problems cited are: lack of information about the illness; lack of help with practical management issues; and inadequate help during crises. Besides feeling neglected by mental health professionals, parents feel that current models of family therapy are guilt-inducing, demoralizing, and generally non-supportive of their role as parents.

In an attempt to address families' needs and concerns, a method of family counseling called "Family Consultation" is the newest approach to meeting the needs of families in a respectful and supportive manner. This model focuses on adaptive strengths rather than weaknesses, incorporates education, and behavioral family therapy (skills building). The basis for this model is the presumption that the family is competent to make choices when given information and education concerning illness and treatment. The family retains the power of choice and is only given consultations at their request. The results of consultation may vary depending upon the needs of the family members.

Bernheim, K.F. & Lehman, A.F. (1985). Teaching mental health trainees to work with families of the chronically mentally ill. Hospital and Community Psychiatry, 36(10), 1109-1111.

Deinstitutionalization has profoundly affected the lives of families who are involved with the care of a relative who has a chronic mental illness. Families must respond not only to the relative's symptoms of the illness but must also negotiate the complex mental health and social service agencies. The need for special training of mental health workers on how to work constructively with families of the mentally ill is discussed. It is suggested that professionals discard theories citing families as causal agents in mental illness and instead concentrate on families as resources with strengths and abilities. In addition, families present educational, emotional, and practical needs in coping with a relative who has a chronic mental illness. The authors propose a two-year curriculum for mental health trainees that combines a set of educational goals with activities designed to broaden the trainee's understanding of mental illness and family participation in treatment.

Persons with a Severe and Persistent Mental Illness



Bernheim, K.F. & Switalski, T. (1988). The Buffalo Family Support Project: Promoting institutional change to meet families' needs. Hospital and Community Psychiatry, 39(6), 663-665.

The authors describe a project begun in 1985 at the Buffalo Psychiatric Center designed to promote family involvement in the treatment of their relative with mental illness. Family members serve as equal participants on the committee directing the project's development and implementation. The project is well supported by hospital administration and has generated numerous training packages, ideas for staff development, and services for families at a low cost and in a form that is easily transferable to other institutions.

Surveys developed and administered to measure the attitudes of family and staff toward each other determined that staff required training in developing empathy with families and in involving them in planning and discharge processes. Staff were offered training sessions focusing on the philosophical basis for the project and its goals, confidentiality in staff-family interactions, understanding the family's perspective, and administrative issues in family involvement.

Five work groups targeting specific issues were formed; two of these groups are described in this article. A work group focusing on treatment planning explored the extent of family involvement and identified obstacles to further involvement: confidentiality, interdisciplinary 'turf' conflicts, and lack of experience in working with families. Policies and procedures to increase family involvement and training opportunities were developed. The second work group focused on family assistance and implemented a 'buddy system', pairing 'experienced' family members with families who were reluctant to become involved.

An audit indicated a substantial increase in family involvement. The evolutionary process of institutional change is emphasized with a gradual development of shared values and goals.

Bernheim, K.F. & Switalski, T. (1988). Mental health staff and patient's relatives: How they view each other. Hospital and Community Psychiatry, 39(1), 63-68.

The Buffalo Family Project, a program at a New York state psychiatric facility, conducted an extensive survey of mental health staff and families of people who have a mental illness to examine their attitudes towards each other and to identify service needs of families. In general, staff expressed positive attitudes towards family involvement in the treatment process, yet cited lack of time as the greatest impediment to good communication with families. In return, the majority of families felt that the mental health staff was supportive, but many relatives still desired more information concerning the patient's illness and treatment. Only twenty-one percent of the families had been invited to treatment planning meetings. The Buffalo Family Project has implemented training programs and administrative changes intended to increase cooperation between staff and patients' families. The article also includes a literature review of other surveys concerning parents' and professionals' attitudes towards the service system and family involvement in treatment.



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Birchwood, M. & Smith, J. (1990). Relatives and patients as partners in the management of schizophrenia. *Psychosocial Rehabilitation Journal*, 13(3), 27-29.

Despite advances in family participation in the treatment of patients with a chronic mental illness, professionals still face a number of challenges in integrating these concepts into clinical practice. The authors discuss three areas of need: engagement of the family in clinical intervention strategies; the limitations of the expressed emotion concept; and the development of a comprehensive and effective service delivery system. Families can be difficult to engage in the treatment process, and family intervention studies in the U.S.A. and U.K. report rates of premature withdrawal from treatment ranging from 8 percent to 35 percent. Factors contributing to withdrawal from treatment include professionals' attitudes toward families, minimization of the illness by family members, and unrealistic expectations for remission of symptoms.

Family members also object to the expressed emotion concept which tends to stereotype families as hostile, uncaring and pathological. The authors do not include a description of the theory of expressed emotion (EE) in this article. This theory tends to underemphasize family strengths and the capacity to change or learn. Interventions with high expressed emotion families focus on reducing the risk of relapse and place little attention on the patient's social functioning or the needs of the care-taking family. To maximize the service delivery system and the family's ability to care for a mentally ill relative professionals must: pro-actively engage families in the treatment process; thoroughly assess family needs and strengths; integrate treatment systems; and participate in on-going training and supervision.

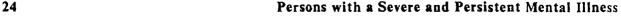
Cole, S. & Cole, D. (1987). Professionals who work with families of the chronic mentally ill: Current status and suggestions for clinical training. In A.B. Hatfield & H.P. Lefley (Eds.), Families of the mentally ill: Coping and adaptation (pp. 278-300). New York: Guilford Press.

Through a review of recent literature, the authors attempt to describe the problems faced by people with severe and chronic schizophrenic disorders, the families of these patients, and the health care system treating them. Included are implications for new directions in training professionals who work with this population. Attention is now given to the objective burdens placed upon the families of the mentally ill such as: decreased earning power of the relative who provides primary care to the patient; deprivations of "normal" siblings; and disruption of important household routines. Relatives become emotionally exhausted when the strain of coping exceeds a family's knowledge, skills and resources.

Studies reveal that family members are eager for professional assistance and feedback concerning how to deal constructively with the relative who has schizophrenia. Specifically the family wants information regarding the nature, course, and treatment of the illness. Numerous studies have shown that "psychoeducational" family treatment is effective in preventing relapses after hospitalization. Several professionals have supported the idea of using multiple family groups as a source of emotional support, informational exchange, and normalization.

Under the leadership of the National Alliance for the Mentally III, the growth of self-help organizations have provided families with the opportunity to discuss their experiences and

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also act as a pressure group to influence policy-makers at local, state, and national levels.

DeChillo, N. (1993). Collaboration between social workers and families of patients with mental illness. Families In Society: The Journal of Contemporary Human Services. In press.

The author examines collaboration between families of the mentally ill and inpatient psychiatric social workers. This study was an assessment of: factors that influence the degree to which families and social workers collaborate; factors that influence the degree of collaboration achieved; and the effects of collaboration on aspects of clinical outcome. Collaboration was conceptualized as the degree to which families and professionals work together and concur that they engage in reciprocal transactions. The sample was comprised of 102 family members of patients and their social workers, who were surveyed around the time of the patient's discharge from the inpatient unit. Findings revealed a relatively high degree of collaboration and indicated that its strongest predictor was the social worker's attitude toward femily involvement in the patient's treatment. In addition, higher levels of collaboration were significantly correlated with increased family involvement in discharge planning and satisfaction with social work services.

Falloon, I.R.H. (1986). Response to Agnes B. Hatfield. Schizophrenia Bulletin, 12(3), 334-336.

The author discusses Dr. Hatfield's thesis that family intervention techniques with schizophrenia patients are hindered by language barriers that portray negative attitudes, thoughts, and behaviors of mental health professionals toward clients' families. Many families continue to harbor a distrust of professionals and experience feelings of alienation from the mental health system. The central issue is whether the semantics of professional literature translates into negative behavior towards families. Many of the families who participate in therapy and research studies have been selected on the basis of the expressed emotion index; a high or low expressed emotion score determines who will receive counseling. Families with low EE scores may be overlooked even though they are in need of support services. Another source of negative feelings on the side of parents is that a patient's treatment goals are set by professionals with little or no input from family members. This author does not agree that a new theory with less critical language will change the attitude and behaviors of family therapists. It is stressed that the family is the best resource for the health of all members, including those with a mental illness. In spite of the complex problems suffered by many of these families, it is the therapist's responsibility to continue to interact with families in a respectful and supportive manner.



Francell, C.G., Conn, V.S. & Gray, D.P. (1988). Families' perceptions of burden of care for chronic mentally ill relatives. Hospital and Community Psychiatry, 39(12), 1296-1300.

The authors report on a research study that utilizes questionnaires and caregiver participation in a focus group. Eighty-six primary care-givers identified two major categories of family burden: providing day-to-day care and interacting with the mental health care delivery system. The focus of this article is on the latter category of family burden.

Several areas were described by caregivers as generating considerable burden: inadequate response in crisis situations; difficulties in accessing entitlement; inadequate community resources; lack of information; a lack in continuity of care; legal restrictions due to confidentiality laws and commitment procedures; participation in family therapy; difficulties in communication with mental health professionals; and family exclusion from treatment decisions. Caregivers expressed the belief that their assessment of their relative's condition should be valued information in the treatment process.

Based on the results from this study the authors offer recommendations for reducing family burden and improving quality of care for individuals with mental illness. Provision of family education and inclusion of families on the treatment team are suggested. Professional influence can be used to work for change in involuntary commitment and confidentiality laws. Improvement of community services is necessary and should include: residential services; social clubs; transportation services; day treatment; and vocational rehabilitation; and mobile crisis treatment teams. Communication with professionals may be enhanced through altering the education of professionals to correct for theories fostering stigma and blame and to increase professional understanding of the needs and feelings of individuals with mental illness and their families.

Grunebaum, H. (1986). Families, patients, and mental health professionals: Toward a new collaboration. American Journal of Psychiatry, 143(11), 1420-1421.

"A variety of family educational- and behavioral-based treatments designed to lower expressed emotion have been found to markedly lower the rate of relapse." These treatment approaches view the family as having to cope with a difficult and tragic illness rather than being the cause of it, and this change in attitude offers the opportunity for mental health professionals and families to work together. Although further research is needed on the relationship between high expressed emotion and sex, culture, socio-economic status, and other factors, groups using psychoeducational techniques with families appear to be very successful in reducing relapse. The initial focus of the groups is to teach families about the etiology, course, and treatment of schizophrenia. Group leaders then attempt to lower expressed emotion by teaching families to comment favorably on desired behaviors, be specific about undesired behaviors, how to offer the patient alternatives, and improve problem-solving skills. The benefits of psychoeducational groups are the improved morale of family members, their ability to learn more effective ways of living with an ill relative, and the encouragement to resume marital and social activities that may have been pushed aside. Families meet other people who have experienced the same fears and concerns for the safety of their children who have schizophrenia.



Grunebaum, H. & Friedman, H. (1988). Building collaborative relationships with families of the mentally ill. Hospital and Community Psychiatry, 39(11), 1183-1187.

"Studies of the expressed emotion construct have demonstrated that educational programs aimed at helping families deal with a mentally ill member can reduce patient relapse rates and improve family coping." A clinical approach to family psychoeducation is described, that focuses on building a collaborative relationship between families and mental health professionals. The authors discuss five tasks that must be addressed in beginning work with families. The tasks include ensuring that the family is listened to, giving information about the patient's illness, helping the family deal with feelings about the illness, identifying the family's coping patterns, and helping the family face conflicts between their own needs and those of the patient.

Hatfield A.B. & Lefley, H.P. (Eds.). (1987). Families of the mentally ill: Coping and adaptation. New York: Guilford Press.

There is currently wide recognition that families can play a significant role in a patient's recovery and integration into the community. Programs are being created with the purpose of helping families deal more effectively with a relative that has a mental illness. There are three basic assumptions that underlie the articles in this book. First, to work successfully with families, professionals must first understand mental illness from the perspective of the family. It is also important that professionals consider the quality of life and well-being of all family members when making treatment plans and assigning responsibilities. Finally, professionals must not assume that there is something wrong with a family that has a member with a mental illness. The difficulties and frustration of coping with mental illness must be understood.

The writers of this book represent a variety of disciplines including psychology, education, nursing, psychiatry, and rehabilitation. Their objective was to focus on the family experience and to develop a theoretical orientation that would encourage understanding of mental illness from the family perspective. In Section 1, the family experience is examined historically and cross-culturally. It appears that a family's ability to cope is greatly influenced by their level of responsibility for direct care and the type and quality of assistance provided by society. In Section 2, the theory of coping and adaptation is applied to families themselves as they come to terms with mental illness in a family member. The effects of mental illness upon the family's social environment are explored. In Section 3, several writers examine the research and practice issues of professionals assisting families with coping and adaptation to an ill family member.

Mental health professionals and families often differ in their perceptions of needs and problems and in the quality of services provided. Growing family consumer strength demands that professionals change their orientation and practice behaviors to meet families on their own level as allies.



Hatfield, A.B. (1990). Family education in mental illness. New York: The Guilford Press.

In this book the author presents curriculum content and methodology for an educational approach towards working with families of persons with mental illness. Section I provides a basic substructure. Five primary influential factors on the social and political context of service delivery are delineated: (1) new definitions of mental illness; (2) changing attitudes toward parents; (3) decisions regarding responsibility for care of persons with mental illness; (4) growth of the consumer movement; and (5) problems with cost of care. The catastrophic nature of the onset of mental illness in a relative is described and the theory of coping and adaptation is recommended as a conceptual framework for understanding the family's dilemma. The family's need to achieve a new balance including the challenges inherent to involvement with the mental health and social services systems is examined. Families are redefined as collaborators rather than as patients with approaches toward helping families that are found to be most consistent with this redefinition emphasized.

Section II provides a knowledge base and curriculum content for educational programs. The most up-to-date information on mental illness is presented and first-person accounts of schizophrenic and depressive experiences are related. Current treatments for mental illness are discussed including risks and benefits of medications and how to monitor them. The authors address the issues of creating a supportive environment, the anticipation and management of crisis situations, and helping families make long-range plans while balancing the needs of all family members.

Section III specifically looks at the process of teaching and includes basic principles of adult education, guidelines for effective learning, and teaching problem-solving skills to families. The book concludes with a warning about the necessity of remaining open to the evolution of new ideas without considering this the ultimate approach.

Hatfield, A.B. (1979). The family as partner in the treatment of mental illness. Hospital & Community Psychiatry, 30(5), 338-340.

"Believing that families are a valuable yet virtually untapped resource in treating and rehabilitating the mentally ill, the author surveyed 89 people to find out how they coped with their relative's long-term illness. Through trial and error, such families have developed a wealth of information about how to live with and manage chronic patients. The author also investigated the types of services and supports families need." Dr. Hatfield identified four priorities of families with a relative who has schizophrenia. The first need is for knowledge about the disease in clear, non-technical language. This includes practical and a propriate techniques for handling disturbing behavior and information regarding resources. Family members also need someone to talk to, such as a sympathetic professional or an organization of other families with similar problems. Respite care for the patient was also a high priority need for families. Parents and relatives need time to strengthen other relationships and to develop their own personal interests. Families also cite a great need for crisis services, especially for professionals who are willing to come to their home. A team approach involving families and professionals is needed in the treatment of people with chronic mental illnesses. Professionals are urged to work with relatives as allies and to devise treatment modalities that make families collaborators in the treatment process.



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Hatfield, A.B. (1987). Systems resistance to effective family coping. New Directions for Mental Health Services, 33, 51-62.

The author examines barriers encountered by families with members who are mentally ill in their search for help in adapting to the trauma they are experiencing. According to literature produced by the families themselves, there is a lack of empathetic understanding by mental health professionals. The mental health ideology attributes the problem to inadequacies in individuals rather than within the environment. Families develop shame and guilt from believing they have caused the mental illness and become alienated from professionals out of pain and rejection. Additionally, the mental health system's credibility has been diminished as a function of the extreme diversity of theory and practice within the field without self-regulation to protect the consumer. A further difficulty with the mental health system is its reliance on family systems theory which does not concern itself with the coping and adaptation of each individual family member.

Legal rights to service are not guaranteed by the U.S. constitution. The discrepancy between "needs" and "rights" is outlined in a historical sketch detailing the paternalism of government during the progressive era and the subsequent movement towards an emphasis on individual rights. This focus on rights to the exclusion of needs has contributed to lack of institutional care for the mentally ill. A more balanced approach to needs and rights is required. Consumers, who are intimately affected by quality of services received for the mentally ill, have no input in assessing quality assurance. This is one of many examples of lack of consumer power in the helping professions. Client satisfaction as an outcome measure is frequently minimized rather than being the focal point of program evaluation.

Hatfield, A.B. (1986). Semantic barriers to family and professional collaboration. Schizophrenia Bulletin, 12(3), 325-333.

Interest has grown in the development of collaborative relationships between mental health professionals and families of individuals with mental illness. Few professionals are trained to work effectively with families in this manner and barriers to collaboration are high. The author discusses how language has contributed to collaborative barriers. Confusion between fact and inference has led to the presentation of opinions, beliefs, and judgments as truth. Families respond with shame, embarrassment and guilt when judgments are presented to them as facts, and the mental health profession loses credibility when no verifiable data support the assertions being made.

Social science literature reflects the "either-or" bias of the English language. This two-valued orientation is an "analytic crudity" that does not reflect the continuum nature of human characteristics. Examples of the use of two-valued orientation with families include: high expressed emotion (EE)/low EE, function/dysfunction, enmeshment/disenmeshment.

Language used by mental health professionals tends to be judgmental and negative toward families rather than focusing on family strengths. Despite avowal of a lack of intent in theories to designate families as causal agents in their relative's mental illness, the author believes that families feel blamed regardless.



The use of technical language by professionals may erect counterproductive barriers. Technical language often prevents clients from understanding the therapeutic process and allows the professional to exert control over the client. Contradictions in professional behavior and attitudes create a confusing situation that forces the family to continually defend itself, thereby limiting the potential for development of a therapeutic alliance. An example of this is when professionals state that families are valued members of the treatment team but then describe the family in negative terms.

Hatfield, A.B. (Ed). (1987). Families of the mentally ill: Meeting the challenges. New Directions for Mental Health Services, 34.

This entire issue of New Directions for Mental Health Services is devoted to the perspective of those who live on a day-to-day basis with mental illness - patients and their families. Chapter One describes the profound effects of one member's mental illness on the rest of the family. Chapters Two through Four focus on the National Alliance for the Mentally Ill (NAMI), a major national family organization, detailing the history and ideology of this movement, the emphasis on consumerism, and the support and self-help activities of local NAMI affiliates. The consequences of stigma are addressed in Chapter Five. Chapters Six and Seven present suggestions for collaborative relationship building between parents and professionals. A personal account of the experience of suffering with mental illness is offered in Chapter Eight. A final overview is provided in Chapter Nine including information on promising new research in the field. The authors presenting in this volume have personal experience in this perspective as they either have a mental illness themselves or are a close relative of a person with mental illness.

Hatfield, A.B. Spaniol, L., & Zipple, A.M. (1987). Expressed emotion: A family perspective. Schizophrenia Bulletin, 13(2), 221-226.

The concept of "expressed emotion" (EE) is examined along with its effect on families who have members with mental illness. Dividing families into dual categories of high EE and low EE is described by the authors as "a crude way of looking at families that is akin to labeling or stereotyping complex human interactions." This type of categorizing encourages professionals to look for the negative in families' interactions rather than for strengths. A result may be to increase alienation between families and professionals preventing the development of partnership. Criticism of the EE concept includes the potential for its inaccuracy in depicting behavior in the natural environment since testing is done during the stressful occasion of hospital admission. Additionally, EE values have been shown to vary cross-culturally and may be an artifact of culture.

Research has shown an association between relapse of patients and high EE, however causality has not been clearly demonstrated. The authors suggest that both high EE and relapse may be a function of other factors such as the failure of the system to help, lack of knowledge and coping strategies, the degree of the patient's dysfunction, and other stressors in the environment.

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The authors suggest that the common ingredient to successful intervention, whether psychoeducation or family therapy, lie in the support offered to parents. Alternatively, families may be receiving a negative message regarding utilization of hospitalization and may be less willing to consider readmittance.

There appears to be a conflict in the goals of mental health professionals and parents regarding placement of individuals with mental illness. Practitioners and policy-makers emphasize families serving as the major caregiving institutions whereas families support community residences rather than the family home as the placement of choice for their relatives with mental illness.

Intagliata, J., Willer, B., & Egri, G. (1988). The role of the family in delivering case management services. New Directions in Mental Health Services, 40, 39-50.

The authors discuss the contributions family members can make to the case management of a relative with a chronic mental illness. It is not suggested that families take primary responsibility for case management of the relative, yet the many ways that families can be powerful natural helpers is presented. The major areas in which families can contribute are assessment, monitoring of services, assistance in daily living, crisis intervention, and advocacy. In order for families to be most effective, it is essential that professionals also pay close attention to the needs of family members to better cope with the daily stresses of caring for a relative with a chronic mental illness.

Johnson, D.L. (1987). Professional-family collaboration. New Directions for Mental Health, 34, 73-79.

The author suggests that communication barriers between professionals and families of the mentally ill are the result of the ideological basis of the mental health system. The psychoanalytic and family systems theories are disliked by families because elements of these theories place the cause of mental illness on the parents. These theories tend to ignore the biological influences of mental illness, yet the biomedical approach is favored by families because emphasis is placed on physical causes and straightforward medical treatment. First, it is possible that a naive collusion develops between the patient and the therapist about the memories that the child or youth may have of the family. A patient who suffers from a mental illness may selectively recall and distort experiences from the past. Second, professionals may hold negative views of families because they most often seek help during a crisis, when they are feeling desperate and overwhelmed. The professional may mistakenly assume that the family members typically act in this manner all the time rather than just during a period of crisis. The author feels that changing methods of training mental health professionals is the only way to overcome the pervasively negative attitudes that professionals hold. New theories such as the Diathesis-stress model and the biopsychosocial model incorporate all aspects of the patient's life system rather than focus on one or two areas such as previous theories have done. "Trainers of professionals must realize that theories and practices which create distance between professionals and family members have negative consequences for the treatment of the

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mentally ill."

Lefley, H.P. (1988). Training professionals to work with families of chronic patients. Community Mental Health Journal, 24(4), 338-357.

A multidisciplinary (psychiatry, psychology, social work) training program is presented to prepare clinicians to work collaboratively with the families of persons with chronic mental illness. The author offers an overview of the traditional approaches to family roles showing how models of family psychopathology have been emphasized. Rather than maintaining a narrow focus on psychoeducation (for example, expressed emotion theory), a broadening of education provided to all caregivers as an illness-management strategy is suggested.

The training model includes three core curriculum elements: a comprehensive didactic component which emphasizes a coping and adaptation perspective as opposed to one of family pathology; hands-on practicum experience with patients with chronic mental illness and their families over a period of six months; and input from families other than those involved in one's practicum. The didactic component incorporates relevant theory and research as well as family-clinician interactions, family experiences with mental illness, social policy, and cross-cultural issues. Participants are trained in patient and family education, problem management, supportive counseling, and resource knowledge.

Lefley, H.P. & Johnson, D.L. (Eds.). (1990). Families as allies in treatment of the mentally ill:

New directions for mental health professionals. Washington, DC: American
Psychiatric Press.

This book is an outgrowth of The National Forum on Educating Mental Health Professionals to Work With Families of the Long-Term Mentally III, a conference held in 1986 organized as a joint effort of the National Institute of Mental Health (NIMH) and the National Alliance for the Mentally III (NAMI). The long-range objective of the forum was to modify education of mental health professionals so they would view families of the mentally ill as allies rather than adversaries.

Chapters in Part I of this book address a historical overview of family roles in treatment of mental illness, the realities of experiencing mental illness in the family, contemporary social policy issues, family-provider relationships, and potential research directions. Part II focuses on models for educating professionals and includes ethical and legal considerations, institutional acceptance, and a curriculum guide.

Four major points made in this volume are: (1) recognition of the stress placed on the family by the mental illness of a relative; (2) failure by mental health professionals to offer blame-free services for families based on mutual respect; (3) necessity for a comprehensive range of community based mental health and rehabilitation services to support the coping efforts of families; and (4) potential benefit of a family and professional alliance in training other families and professionals to adopt a sympathetic, non-blaming perspective



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of the impact of mental illness on the family. A separate abstract is included in this bibliography for chapter four (Bernheim, 1990).

McElroy, E. (1987). The beat of a different drummer. In A.B. Hatfield & H.P. Lefley (Eds.), Families of the mentally ill: Coping and adaptation. New York: The Guilford Press.

The author describes the disparate perceptions held by families of the seriously mentally ill and the professionals who treat them with regard to the needs of families and the quality of mental health services received. Previous research conducted by the author illustrates this disparity and is presented. The need of families to have knowledge about mental illness and treatment procedures in order to be responsible consumers is emphasized. Inclusion of families in discharge planning from inpatient hospitalization is discussed in conjunction with the family's role as principal caregiver for their relative with mental illness.

Family members are reframed as adult learners rather than "unidentified patients." An educational approach that views adult learners as mature, self-directed, decision-makers is suggested as conducive to the development of a therapeutic alliance between families and professionals. Theories of family causation in the etiology of mental illness are unsupported by research, and treatment plans based on these theories are likely to produce resistance from families and increase family distress.

McElroy, E.M. (1987). Sources of distress among families of the hospitalized mentally ill. New Directions for Mental Health Services, 34, 61-71.

The author describes negative experiences families of the mentally ill had in hospital settings and discusses how this has produced alienation from mental health professionals. The use of psychogenic or sociogenic theories of etiology by family therapists has encouraged presumption of guilt on the part of the family and unnecessarily contributes to the family's burden and distress. It is suggested that, at the least, the family should be informed of the theoretical orientation of the staff.

Two common methods involving breach of the family's rights of confidentiality are examined: the disclosure of unsubstantiated allegations by a professional to others and the use of videotaping and student observation without prior consent. Families should be informed of the limits of confidentiality so they may choose whether to participate. Voluntary consent for any observation or videotaping, at least one week prior to the occasion, is suggested along with a full description of the purpose, permission for families to view their videotapes, and information regarding considerations of family privacy in storage procedures of videotapes.

The provision of active psychiatric treatment rather than merely skilled care or custodial care as a condition of federal reimbursement to hospitals and what this means in terms of treatment is detailed. The inappropriate overuse of body searches and seclusion in hospital settings is examined. Throughout, the authors recommend methods for families to obtain relevant information regarding hospital procedures and how to address grievances.

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Pfeiffer, E.J., & Mostek, M. (1991). Services for families of people with mental illness. Hospital and Community Psychiatry, 42(3), 262-264.

The authors report on a roundtable discussion by 26 mental health professionals regarding service provision to families of persons with mental illness. This discussion was sponsored by the Training and Education Center (TEC) Network during the 1989 Institute on Hospital and Community Psychiatry in Philadelphia.

Three dynamics are noted to influence the development of models for working with families. The first dynamic, expressed emotion theory, suggests that improving the ability of families to moderate the emotional intensity of their interactions has a positive impact on lowering hospitalization recidivism for their relative with mental illness. Enhancing professional collaboration with families in their role as the primary community support for individuals with a mental illness is the second dynamic. The third dynamic is represented by families and family organizations advocating for services designed to meet their needs.

Three broad categories of programs for families are identified. Educational programs present information about mental illness and provide training in coping skills; they usually do not include the relative with mental illness. Treatment-oriented models include the whole family and focus on developing adaptive problem solving and communication skills. Empowerment programs place full treatment authority with the family with professionals serving as resources or assistants.

The discussion focused on topics such as "whether the field should treat or teach," how to facilitate retention of information and skills, provider-family relationships, meeting family needs, and research issues. An interesting suggestion, made by the director of the TEC Network, involved the use of a peer consultant acting as a fully empowered co-facilitator to reduce family anxiety by modeling how family members and mental health professionals can collaborate.

Rosenson, M.K. (1987). Model for a new relationship: Professionals and families working together to build community services. *International Journal of Mental Health*, 14(4), 94-108.

A community rehabilitation center for adults with chronic mental illnesses is described. This center in New Orleans was created through the combined efforts of parents and professionals and is run by a board of directors that consists of family members, friends, and other concerned citizens. The project is unique because it builds upon the strengths of families and utilizes those strengths to accomplish goals. The service center, called the Friendship Club, provides a variety of services including case management, socialization programs, vocational training, and transitional employment opportunities. The patients are encouraged step-by-step to take on more responsibility for their own activities and lifestyle. In addition to overseeing the general program, parents on the board of directors also focus attention on finding suitable housing for patients, educating police about the special needs of this population, and the development of a crisis center. Family support groups and educational groups are also provided at the center. Patients who are served at the Friendship Club have a chronic mental illness and have recently been discharged from hospitals or residential facilities. The services provided aid readjustment to society by helping people to acquire necessary skills for life in the community.

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Spaniol, L., Jung, H., Zipple, A. & Fitzgerald, S. (1987). Families as a resource in the rehabilitation of the severely psychiatrically disabled. In A.B. Hatfield & H.P. Lefley (Eds.), Families of the mentally ill: Coping and adaptation (pp. 167-188). New York: Guilford Press.

The current emphasis on community-based treatment approaches has resulted in shorter periods of hospitalization and the use of a wide array of aftercare and rehabilitative services. Large numbers of people with psychiatric disabilities are returning to live with their families (as high as 70%). Although families have become the primary caregivers for people who have a chronic mental illness, they frequently lack the information, skills, and resources to adequately assist their relative. Mental health professionals need to concentrate on identifying family needs and strengths as well as find ways to maximize the positive influences of the family. The purpose of the current study was to identify family needs and coping strengths, as well as the perceptions of mental health professionals. A national sample of 140 families was developed from the membership list of the National Alliance for the Mentally Ill. The demographic characteristics of the respondents to the questionnaire were predominantly white, female, over 50 years of age, with high levels of education and professional or managerial jobs. The results of the family needs survey showed that overall dissatisfaction with mental health services were high. The specific services named as inadequate included social rehabilitation, drug medication, and vocational rehabilitation. Of the family respondents, 53% reported having contact with a professional only once every two months or less. These family members wanted much more frequent contacts to discuss the patient as well as the family's needs and concerns as a

Wintersteen, R.T. & Young, L. (1988). Effective professional collaboration with family support groups. *Psychosocial Rehabilitation Journal*, 12(1), 19-31.

Fifty-four members of support groups for families of a person with a mental illness were interviewed to assess the roles, actions and attitudes of professionals who work with support groups. The respondents were all active members in family support groups and expressed high levels of satisfaction with the leadership and emotional climate of their groups. Ninety-six percent of the respondents supported the role of a professional advisor and felt an advisor would aid in general group functioning. In spite of their positive attitudes, the participants expressed certain perceived risks when professionals are involved in support groups. The families were concerned that a professional may attempt to dominate a group, may harbor negative or patronizing attitudes toward families, and may provide false or outdated information. The authors propose ten principles to be used as a guideline for the relationship between professionals and members of family support groups. These principles include: the professional's role as a liaison and resource person, as opposed to a therapist or leader; giving ownership of the group to the members and allowing them to select their own leaders; being aware of members' sensitivity to patronizing or stigmatizing attitudes from professionals; and the goal of eliminating these attitudes from one's personal and agency behaviors.



Persons with a Severe and Persistent Mental Illness

Zipple, A.M., Langle S., Spaniol, L. & Fisher, H. (1990). Client confidentiality and the family's need to know: Strategies for resolving the conflict. Community Mental Health Journal, 26(6), 533-545.

The authors discuss perceived conflicts involved in providing information to families without jeopardizing the rights of confidentiality of the individual with mental illness. Research is cited that offers evidence for decreased frequency of relapse among family members with mental illness when information about the mental illness is provided to the family. According to several studies, professionals frequently do not give this information to families. A significant factor in the reluctance of professionals to disclose information to families is believed to be out of concern for protection of clients' rights to confidentiality.

Legal issues in confidentiality are explored including court cases in which access to mental health information were addressed. Strategies for resolving the conflict due to confidentiality requirements are suggested. The authors find most clients to be willing to involve family members if requested by a professional who values family participation. Including family members on the treatment team with the consent of the client allows the family full access to information and contact with other providers. Family members play a significant role on the treatment team by sharing perceptions of their relative's strengths and pre-hospitalization functioning.



Persons with a Severe and Persistent Mental Illness

## CHILDREN WITH SERIOUS EMOTIONAL DISORDERS



Byalin, K. (1990). Parent empowerment: A treatment strategy for hospitalized adolescents. Hospital and Community Psychiatry, 41(1), 89-90.

The authors report on a program in which the average length of stay at an inpatient adolescent psychiatric unit at South Beach Psychiatric Center in Staten Island, New York has been reduced from one year to less than four months through the use of a parent empowerment program. A breakdown in parental authority is cited as a global reason for the hospitalization of adolescents, and the re-establishment of parental control is considered to be the primary intervention. Parents are encouraged to define treatment objectives for their child, participate in developing strategies for goal achievement, and finally decide on the timing of the child's discharge from the hospital. Throughout this process parents regain their confidence and authority, eventually participating in family therapy sessions with the adolescent. Through the use of this program and group parent support meetings the families seem able to maintain progress made during the adolescent's hospital stay.

Collins, B. & Collins, T. (1990). Parent-professional relationships in the treatment of seriously emotionally disturbed children and adolescents. Social Work, 35(6), 522-527.

Parent involvement has been promoted in policy and program guidelines through the impetus of parents; however the reality of parent-professional relationships do not yet reflect this principle of parent involvement. The authors describe characteristics of "full parental involvement" as communicated by members of the Parents Involved Network and the Federation of Families for Children's Mental Health: acceptance as full-fledged members of the multi-disciplinary team; sharing of all relevant information on which planning and decision-making is based; communication free of jargon, patronizing and blame-laden language; focus on family strengths as well as needs; and joint decision-making by parents, professionals, and the clients themselves whenever possible.

Professional attitudes toward parents are seen as barriers to change. Blaming attitudes which portray parents as pathogenic agents responsible for their children's mental health problems may be a reflection of a cultural tendency to blame mothers. The conceptual basis of professional-client relationship with its inherent power inequity results in a hierarchical relationship focused on parents' deficiencies. Feminist/empowerment-based practice is suggested as a means for developing egalitarian and collaborative client-social worker relationships by emphasizing client efficacy and strength and by supplying "power resources" such as information, knowledge, attitudes and interpersonal skills to help families effectively work with social systems and organizations.

The authors specify a need for research documenting professionals' view of the parent-professional relationship in order to develop training and educational programs that help professionals move beyond the attitudinal obstacles to parent-professional collaboration.

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Collins, B.G. & Collins, T.M. (1990). Professional responses to parent involvement in treatment planning. In A. Algarin & R.M. Friedman (Eds.), Proceedings of the third annual conference. A system of care for children's mental health: Building a research base. (pp. 247-256). Tampa, FL: Research and Training Center for Children's Mental Health, Florida Mental Health Institute.

According to the authors "much of the impetus for a changed parent-professional relationship has come from parents - not professionals." Parents have described the following dimensions as important to enhancing parent-professional relationship in support of full parent involvement: (1) acceptance of parents as full-fledged members of treatment teams; (2) professional willingness to share all relevant information; (3) two-way, jargon-free communication; (4) focus of treatment planning on strengths and assets of child and family as well as needs; and (5) joint decision-making between parents and professionals.

Review of research literature reveals minimal attention to the effects of parent advocacy efforts on the parent-professional relationship. The authors describe a research study they have designed involving focus groups to assess professional attitudes toward parent involvement. Examination of professional attitudinal and ideological barriers to collaborative parent-professional relationships will facilitate development of educational and training programs to address these issues.

Donner, R.P. (1986). Social workers' view of parents of children with emotional disturbances: A problem or partner in the solution. Unpublished manuscript. Lawrence, KS: University of Kansas, School of Social Welfare.

An historical review is presented of mental health professionals' perception of parents as a cause of their children's emotional disorders. Through a literature review, the author documents the shift, which has occurred in the last twenty years, away from a family blame perspective towards a more collaborative view. It is suggested that social work as a profession has veered from a focus on values and that integration of values into practice will be needed to support this changing view of parents. Partnership between parents and workers is presented as an extension of collaborative approaches. Drawing on social work values in the development and maintenance of partnership would entail: (1) treating parents with respect and dignity; (2) building the partnership on honesty and mutual understanding; (3) acknowledging the expertise that parents have about their child and responding to what they state are their needs; and (4) having parents share in the definitions of the problem and in the decisions about possible solutions. Suggestions for new information to expand the knowledge base of social workers is offered.

Finkelstein, N.E. (1974). Family participation in residential treatment. Child Welfare, 53(9), 571-575.

The author presents methods and interventions for integrating families into the therapeutic process of residential treatment for children with emotional disorders. Children in

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residential treatment often come from homes with multiple problems and mental health workers have the complex task of defining the target area for change. At times the focus of treatment may be the child alone, the family, or the extended family system. Parental involvement and support of long-term agency care is of vital importance for a child's acceptance of self and the child's ability to benefit from therapeutic treatment. It is recommended that parents become involved in the treatment milieu and become familiar with treatment and parenting methods used in the residential environment. In turn, child care workers could accompany the child on home visits and become familiar with the family's system of communication and lifestyle. Eventually a child care worker and the parent may find ways to integrate common methods of behavior management and emotional support into the home environment. Through the high involvement of family members and the use of collaboration on behalf of the child, the length of stay in residential treatment could be greatly reduced.

Friesen, B.J. (1989). Survey of parents whose children have serious emotional disorders: Report of a national study. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

The author reports on a study involving national distribution of questionnaires to parents whose children have serious emotional disorders. Recommendations are offered based on the information obtained in the nearly one thousand responses. It is suggested that mechanisms for mental health financing and child welfare policy need to be reexamined in the light of the result that one quarter of the parents had been informed that relinquishing legal custody of their children would improve access to services. As nearly one half of the parents reported being physically threatened by their children, information on how to deal with assaultive children and concrete assistance is necessary.

Honesty; a respectful, non-blaming attitude; supportiveness to the child and to the parents; and efforts to include parents in decision-making were all rated as "very important" professional behaviors by a great majority of parents. Financial assistance, support groups for brothers and sisters as well as parents, and respite care were all services that parents identified as particularly difficult to obtain. Informational needs identified by parents included: assessment, available treatment, causes of the disorder, how to cope with raising a child with an emotional disorder, and long-range (transitional) planning. Heavy caregiving burdens with insufficient relief were reported as adversely affecting family life. Informal support was received from a variety of sources, especially friends and relatives, with emotional support being the most helpful aspect of informal support.

The use of this information in professional educational programs is suggested. Parents' identification of the importance of association with other parents in similar circumstances is consistent with efforts to expand availability of parent support groups. The significance of religion as a source of coping for family members suggests a need for further research in this area and for program development to enhance the involvement of churches and other religious organizations.

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Kelker, K.A. (1987). Working together: The parent/professional relationship. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

This is a workshop curriculum designed with the goal of identifying "the basis of understanding and cooperation between professionals and parents of emotionally handicapped children." Participation in the workshop should consist equally of parents of children with emotional disorders and professionals in the mental health and/or special education fields. The format of the workshop involves self-analysis and team work. It allows for the venting of feelings that parents and professionals have for each other, for demonstrations of parents and professionals working together as teams, and for constructing suggestions for improved means of collaboration. Objectives of the workshop include: identifying stressors on both parties; identifying the basis for cooperation; discovering obstacles to cooperation; demonstrating and practicing effective listening techniques; practicing team decision-making; and examining attitudes of the parties toward each other.

McConachie, H. (1986). Parents and young mentally handicapped children. Cambridge, MA: Brookline Books.

A literature review is utilized to develop a conceptual framework for involvement of parents in the teaching of their young children with mental disabilities. The authors emphasize the importance of recognizing the interdependence of children's development and their environment as well as the different levels of systems in which the child is a participant - parent-child interaction, the home, the extended family, the community, and the culture of the child's society. These ecological principles guide the focus on parental and professional partnership with parents recognized as the most salient figure in a child's environment. Research evidence regarding the family life of children with mental disabilities is reviewed and critiqued. Parents' reactions to a child with disabilities is explored. The interaction between parents and children, both with and without disabilities, and how this interaction contributes to development is examined. The rapidly-increasing body of literature on parents as teachers to their young children with disabilities is reviewed with an emphasis on the use of differential program designs with differential parent characteristics.

McManus, M.C. & Friesen, B.J. (1986). Annotated bibliography. Parents of emotionally handicapped children: Needs, resources, and relationships with professionals. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

This document is an annotated bibliography of the literature pertaining to two general topic areas: (1) parent-professional relationships and (2) organizations for or of parents with children with emotional disorders. The bibliography is divided into seven categories that reflect major themes of the literature. In the section on parent-professional relationships, the focus of the literature is on suggestions for relationship improvements, but little research is available about the actual behavior of parents and professionals. Two



sections discuss parent groups and are divided on the basis of whether the groups are professionally organized and led or are self-help oriented. Two sections address parent participation in the helping and education processes. A section on parents' problems, needs, and characteristics examines available research on parents of children with emotional disorders. In the last section, literature designed to increase skills in enhancing parent/professional relationships is presented. The authors emphasize the lack of research in this area and suggest that this limitation "points to an agenda for the future."

McManus, M.C. & Friesen, B.J. (Eds.). (1986). Families as Allies conference proceedings, Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

Sponsored by the Research and Training Center on Family Support and Children's Mental Health and by CASSP Technical Assistance Center, the mission of this conference "was to promote collaborative working relationships between professionals and parents of seriously emotionally handicapped children and adolescents." In attendance were representatives from thirteen western states including policy-making, administrative, and service delivery professionals from the major public systems that serve children with emotional disorders: private service providers; and parents of children and adolescents with emotional disorders. The conference was organized with two panel discussions that focused on obstacles to parent-professional collaboration and methods of overcoming these barriers. Parent blaming, induced by theories of etiology of mental illness which cast parents as pathological agents, was viewed as a serious obstacle to parent-professional collaboration. Constraints and requirements of agency policy and limitations imposed by funding sources were described as additional obstacles. The most important means to improve parent-professional relationships demands an attitudinal change toward viewing parents and professionals as equals. Issues of parent empowerment and the value of parents' developing skills and knowledge were also discussed. Another focus of the conference was for state delegations to generate action plans to facilitate increasing parent-professional collaboration in order to improve the states' services for children with scrious emotional disorders.

Poertner, J. & Ronnau, J. (1989, February-March). The Family Advocacy Case Management Model: An innovative approach to meeting the needs of families caring for youth with emotional disabilities. Second Annual Conference Proceedings. Children's Mental Health Services and Policy: Building a Research Base, 142-150. Tampa, FL: Research and Training Center for Children's Mental Health, Florida Mental Health Institute.

The authors describe The Family Advocacy Case Management (FACM) model that has been implemented in a community mental health center and a state hospital in the last four years. "The core of the FACM model is referred to as a 'strengths approach': relating to, working with, and assisting clients by identifying and making use of their personal and community assets." Emotional disturbance in a child is reframed as a disability rather than a mental illness to reduce the hopelessness and stigma associated with the term mental illness.



The development of a positive working relationship between the case manager and the family caregivers is an essential element of this model. The following techniques are utilized to promote relationship building: meeting with the family at their home; involving the family in identifying objectives and strategies to achieve them; providing information about the youth's disability; obtaining resources; and using empathy and listening skills. The standards for setting objectives include stating objectives in positive terms with a family and/or youth orientation. Objectives are focused on resource acquisition rather than on behavior or psychological changes. Group supervision is used to ensure that the focus remains on family strengths and that standards for objectives are maintained. Group supervision also provides support for case managers and brainstorming of ideas and resource suggestions.

Thompson, M.G.G. (1983). Guiding a therapeutic relationship with parents of seriously disturbed preschoolers. *The Social Worker*, 51(2), 49-51.

The parents of children with serious emotional disorders may find themselves in a number of roles including client, colleague, patient, and parent. The author examines the parents' initial role as a client and how this can be combined with their role as a colleague in their child's treatment plan. A therapist must pay attention to the parents' need to mourn "the child who might have been" and their passage through the stages of mourning; denial, protest, bargaining, despair, and reorientation. Gradually as parents come to terms with their loss, they begin to make constructive use of available resources to help themselves and their child. As well as guiding the mourning process, the therapist must concurrently make steps to establish the parents' place as colleagues by clarifying the nature of the illness and outlining plans for treatment. Parents may work with the therapist to learn behavior modification techniques that can be used in the home environment. In summary, therapists must first assess and direct assistance to factors which are related to the nourning process and the family's ability to cope and handle stressful events.

Van Den Berg, J. & Donner, R. (1986). Parents and mental health program leaders: Working together in Kansas. Children Today, 15(3), 22-25.

The Family Input Program of Kansas has developed a format that encourages the parents of children and adolescents with severe emotional difficulties to help in developing services systems and the establishment of community-based services. This National Institute of Mental Health (NIMH) project supports the Child and Adolescent Service System Program (CASSP) initiative to focus on the development of services to children and adolescents with severe emotional problems. Early psychoanalytic and family systems theories emphasized the parents' and families' influence on the development of emotional problems in children, and parents have often been seen as barriers to treatment. Both of these theories engender feelings of guilt and alienate families from social service agencies. The Family Input Program is based on the idea that parents can be engaged in non-blaming ways in their child's treatment process. Parents are viewed as the real "experts" regarding their children's needs. The program organizes forums for parents of children with severe emotional difficulties to meet in a supportive environment and discuss actions that can be taken to



advocate for advances on issues pertinent to social services for children. The forums are facilitated by a representative from a state agency and are held in community halls or churches. These meetings are taped and reviewed by directors of agencies to understand what issues are most important to parents and to also receive ideas from the social service consumers. Parents offer a perspective that is comprehensive and unique. Each academic discipline tends to train students to look at children in different ways, and often the only people who can see the whole child are the parents.

Vosler-Hunter, R. & Exo, K. (1987). Working together: A training handbook for parent-professional collaboration. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

This training manual, developed for a parent-professional collaboration project to improve services for children with emotional disorders, consists of a collection of training exercises designed to promote partnership skills between parents of children with emotional disorders and the professionals who serve them. Areas of emphasis include: communication skills, problem solving skills, identification of attitudinal and system barriers, strategies to overcome barriers, and background information and resources concerning emotional disabilities.

Vosler-Hunter, R. (1989/1990). Families and professionals working together: Issues and opportunities. *Focal Point*, 4(1), 1-4. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

"A collaborative relationship between parents and professionals will help ensure that services provided to the family are based on a thorough understanding and response to family-identified needs and priorities, support family strengths in meeting needs, and promote the family's ability to acquire and sustain resources for problem solving." To promote success in collaboration efforts, the author identifies factors inhibiting collaboration and key elements of successful collaboration. Factors influencing or inhibiting collaboration include: the beliefs and perceptions regarding mental illness and emotional disability of both parents and professionals; prior experiences of parents with service delivery; the external demands exerted on both parents and professionals by work and family life; cultural differences; and socioeconomic and educational influences. Key elements of collaboration are described by the author as: mutual respect for skills and knowledge; honest and clear communication; sharing of information; mutually agreed upon goals; and shared planning and decision-making.



Vosler-Hunter, R. (1989). Changing roles, changing relationships: Parent-professional collaboration on behalf of children with emotional disabilities. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

Written for family members and direct service providers, this monograph presents a rationale for parent-professional collaboration to improve services for children with emotional disabilities, and a discussion of interpersonal and practice skills that promote collaborative interaction. Strategies to enhance a collaborative relationship are provided for both parents and professionals. Appendix items include checklists on effective collaboration for parents, professionals and professional training programs, and policy makers, as well as listings of organizations and publications related to collaboration.

Vosler-Hunter, R. and Fisher, E. (1992). Families As Allies: Building a Family-Centered System of Care Conference Proceedings. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

The Families As Allies: Building a Family-Centered System of Care conference was held in Portland, Oregon in May 1991. The primary objectives of this conference were threefold: (1) to promote collaboration between family members and professionals to improve services for children with emotional disorders; (2) to share developments and initiatives among participating state delegations; and (3) to develop state plans and strategies of action to encourage the development of family-centered services and policies. To meet these objectives workshop sessions focused upon methods of improving relationships between professionals and family members, increasing the involvement of family members in policy and service planning, and promoting and maintaining family support and advocacy groups. Participants represented a broad range of service providers and family members from eleven western states. Conference proceedings include: (1) the conference agenda; (2) edited transcriptions of speeches and panel presentations; (3) state delegation recommendations and action plans; (4) participant worksheets; and (5) a summary of conference evaluation responses.

Williams, B.E. (1988). Parents and patients: Members of an interdisciplinary team on an adolescent inpatient unit. Clinical Social Work Journal, 16(1), 78-91.

The authors describe the inclusion of patients and parents in treatment team decisions on a psychiatric inpatient unit. Discussion focuses on the process of inclusion as well as resistance to inclusion of family members. "The inclusion of the family in the treatment team changed the quality of the parent/professional interaction.... It was acknowledged up front that the parents knew the child better and were more important to him/her than any transient hospital staff could ever be.... This was an alliance which built on the strengths of parents" (p. 88). Dissension between parents and professionals was minimized by this process and hospital stays were significantly shortened.



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## CHILDREN WITH OTHER DISABILITIES



Alexander, R. & Tompkins-Mcgill, P. (1987). Notes to the experts from the parent of a handicapped child. Social Work, 32(4), 361-362.

For parents of children with disabilities the search for appropriate services and responsive professionals can be a frustrating process. One mother discusses the need for a positive and supportive relationship between parents and professionals. The impact of professionals' attitudes and methods of communication on families is presented in terms of one author's experiences with medical and social service agencies. Recommendations emphasize methods of improving communication patterns and the importance of treating parents as valuable resources in the development and implementation of a child's treatment plan. The success of intervention methods is dependent upon the parents' involvement and their sense that the system is responsive to the needs of the child.

Blackard, M.K. & Barsh, E.T. (1982). Parents' and professionals' perceptions of the handicapped child's impact on the family. Journal of the Association for Persons with Severe Handicaps, 7(2), 62-70.

The authors examine a professional's ability to understand and accurately predict the impact of a child with a disability on family functioning. Forty-five parents and one hundred special education professionals participated in the survey. The study explored how parents describe the impact of their child with a disability on the areas of family relationships, community resources and acceptance, home teaching, and behavior management techniques, and the extent of agreement or disagreement with the perceptions of professionals in these same areas.

Significant differences were found between the parent and professional responses in that professionals over-estimated the negative impact of a child with a disability on the following situations: marital and family relationships, community acceptance, financial costs, and the family's ability to utilize resources. In addition, the professionals under-estimated the parents' ability to use appropriate teaching methods and behavior management techniques in the home. The needs of families with children who have disabilities and the importance of individual family assessment and planning are discussed in light of these findings.

Donnellan, A.M. & Mirenda, P.L. (1984). Issues related to professional involvement with families of individuals with autism and other severe handicaps. *Journal of the Association for Persons with Severe Handicaps*, 9(1), 16-25.

The authors address the development of non-productive parent-professional relationships related to autism and offer recommendations of new standards to adopt to improve this situation. In line with current research, all interventions should be based on a model that does not attribute the cause of autism to parent or environmental pathology. The negative impact of this historical misconception of parent blame should be acknowledged. Professionals should be aware of their own values and biases and guard against inflicting them upon families. In accordance with the "criterion of least dangerous assumption," any

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intervention that is ineffective should be assumed to be a function of programmatic inadequacy rather than family defect. Full information should be provided to parents regarding the possibility of autism even if the diagnosis in inconclusive. Families' emotional and practical problems of dealing with autism should be accepted as legitimate reactions to an overwhelming situation. Emotional and support services should be readily available to families who want them but it should not be assumed that all families need these services. Services should be provided to all individuals with severe disabilities, regardless of age. Families should be involved to a maximum extent in all intervention programs but their right to choose lesser involvement should be acknowledged. Not only should the needs of the child with autism be considered but, also, the needs of the entire family system. Parents should be offered full membership on the treatment team in recognition of their expertise about to their child. Access to information should be provided to parents, and the intervention program should be accountable to the family for its effectiveness.

Fine, M.J. (Ed.). (1991a). Collaboration with parents of exceptional children. Brandon, VT: Clinical Psychology Publishing Company.

"It is in the theme of viewing parents as collaborators or partners with the professional community in the care, treatment, and education of their exceptional child that this book has been written." In accordance with this theme emphasis is placed on providing parents with skills necessary to help themselves and their children through education and empowerment. Models of collaboration and empowerment are presented in the first two chapters. Topics of other chapters include: variations in parenting/family structures, counseling approaches, and abuse. Several chapters focus on specific exceptionalities: developmental disabilities, chronic illness, learning disabilities, autism, and giftedness. The last section of the book contains chapters discussing sexuality, transitions, and advocacy. Chapters One (Fine, 1991b) and Two (Dunst et al., 1991) are reviewed separately in this bibliography.

Fine, M.J. (1991b). The handicapped child and the family: Implications for professionals. In M.J. Fine (Ed.), Collaboration with parents of exceptional children (pp. 3-24). Brandon, VT: Clinical Psychology Publishing Company.

As part of a book on parent/professional collaboration, the perspective of this chapter emphasizes "the need of involved professionals to a) understand normal family development, b) appreciate individual variations among families with a handicapped member, and c) develop a collaborative orientation to working with parents and families." The first section looks at individualized family assessment by examining general concepts of family functioning such as: the family as a system, ethnic/cultural considerations, life cycle considerations, boundaries and hierarchies, enmeshment-disengagement, and intimacy and communication. The second section explores the impact of the exceptional child on the family. The unique nature of each family's process is emphasized and the concept of "chronic sorrow" is used to reflect the family's need to adapt to changes in circumstances over the life cycle.

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The last section of the chapter details a collaborative model of parent involvement. The model represents an attitudinal set developed by professionals in relation to parents of exceptional children in which the importance of collaboration is recognized. The model acknowledges that parents may not initially be ready for full collaborative participation and promotes activities that move parents towards greater participation. In line with this model the helping professional takes on multiple roles such as consultant, mediator, advocate, therapist, and expert. The model stresses problem-solving and views parents as teachers as well as learners.

Hermary, M.E. & Rempel, J. (1990). Parental and staff perceptions of individual programming teams: Collaboration in and beyond the conference. Education and Training in Mental Retardation, 25(1), 25-32.

The authors report on a research study conducted to examine parental and staff perceptions of Individual Program Teams (IPTs) at a community-based agency providing day training and/or residential services to adults with mental disabilities. Yearly IPT conferences are held to establish and evaluate goals and objectives. All individuals involved with the client join the client in attending the conference. During the year the team members develop programs to carry out the planned objectives.

A questionnaire, which included three general and six conference-specific items, was distributed to all staff and a random sample of parents. Results indicated three areas of significant discrepancy between perceptions of staff and parents. In regards to team cohesiveness, a mixed response was received from parents concerning whether or not they felt like part of their respective teams while staff gave a more positive assessment of team cohesiveness. In looking at conference comprehensibility, staff indicated low comprehensibility while parents again provided a mixed response. Parents' perception of the equality of participation in conferences was far more positive than the mixed response given by staff. The authors speculate that perception of participant equality may have different meanings to the respondents; equality may mean being respected as an equal to parents and may have more of a quantitative notion for staff. Participatory equality was significantly and positively correlated with perceptions of conference utility for both staff and parents but was negatively correlated to formality for parents.

The authors emphasize this study's attempt to examine not only the IPT conference but also the IPT process outside the annual conference setting. The importance of parent-staff teamwork in the process of carrying out the integrated plan is stressed.

Lipsky, D.K. (Ed.). (1987). Family supports for families with a disabled member, (Monograph No. 39). New York: International Exchange of Experts and Information in Rehabilitation, World Rehabilitation Fund, Inc.

The International Exchange of Experts and Information in Rehabilitation produces yearly fellowship reports prepared by U.S. experts who have studied social service issues in foreign countries. This monograph focuses on the topic of family support systems and presents

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articles on types of family support in England, Canada, Sweden, and Israel. Family support services have increasingly become part of the system that serves individuals with disabilities due to the realization that the consequences of a disability affect not only the individual but also the members of the person's family. The rationale behind family support is to enable the family to continue functioning as a healthy and cohesive unit - "an intact family offers stability, consistency, and close relationships which cannot be duplicated . . .".

Services that may be needed by a family include outreach, caregiver training, counseling, respite care, transportation, financial or housing assistance, and crisis intervention. Articles from Israel, England, and Canada discuss the various issues in understanding and assessing families' needs. Enhancing and supporting parental power and a working partnership between parents and professionals are a primary focus of the authors. Articles from Sweden and Israel focus on actual service systems designed to work with families in order to avoid institutionalization of the individual with a disability through support and compensation methods.

Mesibov, G.B. & La Greca, A.M. (1981). Ethical issues in parent-professional service interaction. In J.L. Paul (Ed.), *Understanding and working with parents of children with special needs*. New York: Holt, Rinehard & Winston.

The authors describe special issues concerning the challenge of integrating the different perspectives of parents and professionals into parent-professional partnerships in serving the needs of children with disabilities. Accessibility of treatment services to parents is considered in terms of the rights of parents, rather than professionals, to make major decisions for their children. Development of a mutuality in the working relationship between parents and professionals is stressed. The authors examine the question "Who is the professional's client?" when the rights of the parent come in conflict with the rights of the child. The professional role as facilitator rather than decision-maker is described in establishing realistic and appropriate treatment goals that are congruent with the parents' priorities. The authors emphasize the value of parental input in assessing the appropriate use of the normalization process for each individual child. Parents' rights regarding access to information is explored in relation to professional concerns for creating strain in the parent-professional relationship due to the sensitive nature of recorded information. Conflicts between clinical needs and research goals are examined.

Mittler, P., Cheseldine, S. & McConachie, H. (1981). The education of the handicapped adolescent: Roles and needs of parents of handicapped adolescents. Paris, France:

Organization for Economic Co-operation and Development, Centre for Educational Research and Innovation.

This article is based on the United Kingdom population and services. The authors' working assumption "is that the main role of parents of handicapped adolescents is fundamentally the same as that of parents of any other adolescent - to provide a loving and secure home and to prepare them to live independently in the community." The article discusses the time



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of school-leaving and the special problems associated with this time. The importance of parental attitudes towards increased autonomy in their adolescents with disabilities is emphasized. Family service needs determined through literature review include: the need for information on the range of provisions offered, for residential and support services, and for financial help.

Partnership between parents and professionals is stressed as the hallmark of good service for children with disabilities. The nature of the partnership should include involvement of parents in assessment and collaboration in long- and short-term goals. The authors envisage home visiting as an ideal format for collaboration. Obstacles to collaboration both from the perspective of parents and from professionals are examined and suggestions made for increasing collaboration.

The needs and rights of adolescents with disabilities are described in accordance with the United Nations Declaration of Rights of Disabled Persons (1975). The right of adolescents to be involved in any planning on their behalf is emphasized.

Mittler, P., Mittler, H. & McConachie, H. (1987). Working together: Guidelines for partnership between professionals and parents of children and young people with disabilities. In D.K. Lipsky (Ed.), Family supports for families with a disabled member (pp. 15-35). New York: International Exchange of Experts and Information in Rehabilitation.

The author suggests using partnership as the central theme for developing a working relationship between professionals and parents of children with disabilities. Areas in which partnership can be stressed are finding common goals of parents and professionals, increasing the parent's ability to be a resource for the child, and increasing the parent's information base regarding the child's disability and appropriate interventions to be used. Key concepts of a partnership include mutual respect, a common purpose, shared feelings, joint decision-making, and flexibility to differing opinions. Professionals who are able to maintain these objectives when interacting with parents will empower the family to seek and pursue services that meet the needs of their child. Promoting parent involvement is vital since parents have essential information regarding their child's special needs. Some of the obstacles to parent/professional collaboration include: lack of training on the part of the professional, psychological and social distance created by the professional role, differing needs of the child and the family, unrealistic expectations, and lack of clarity about the child's capabilities. Professionals must be aware of these areas of difficulty in order to work effectively with the family. Extensive recommendations are made on how to move through problem areas and achieve progress in a parent/professional working relationship. Sharing detailed information with parents is very important as is creating opportunities for extensive contact between service providers and the family. Because parents are consumers of services for children with emotional and physical disabilities, it is important that they become involved in policy reform and participate in the legislative process as well.



Moxley, D.P., Raider, M.C. & Cohen, S.N. (1989). Specifying and facilitating family involvement in services to persons with developmental disabilities. *Child and Adolescent Social Work*, 6(4), 301-312.

The authors support the importance of family involvement in the treatment of people with developmental disabilities and present a definition of involvement that resulted from a qualitative study of family involvement from the parental perspective. Family involvement is identified as having four system levels: the individual, the program/agency, the community, and society. Family involvement also has five role opportunities for family members including treatment agen\*, planner, advocate, evaluator, and consultant/educator. Barriers to family involvement can be classified under three broad categories: resource barriers, training and skill barriers, and communication barriers. The authors outline a process for promoting involvement through contracting, developing a support system, monitoring and evaluation.

Moyers, A.J. (1989). Parents as case managers. New Ways, Winter, 20-21.

Counties in California and Minnesota have established programs to train parents to act as case managers for their children with disabilities. In Orange County, California, parents attend a five week parent advocacy training, serve a one year apprenticeship under a supervisor, and finally work independently as parent program coordinators (PPC). The coursework and practical experience includes learning how to fill out necessary paperwork and accessing community and support services for their children. Parent Program Coordinators are divided into two supervised groups according to whether the family member with disabilities is a child or an adult. Three counties in Minnesota have modeled a training program after the California PPC Program. In addition to training and support systems, the Minnesota parents receive a small stipend for their work as parent case managers. A one year evaluation report on the program indicated positive and cooperative relationships exist between county case managers and parent case managers. Parents reported feeling empowered, knowledgeable, and less stressed in their abilities to access and coordinate services for their children with disabilities. The follow-up report recommended giving parent case managers the authority to authorize special services for their children because of the parents' intimate knowledge of the children's needs.

Mulick, J.A. & Pucschel, S.M. (1983). Parent-professional partnerships in developmental disability services. Cambridge, MA: Academic Guild Publishers.

The authors examine some of the psychological and educational barriers evident in the attitudes of professionals and parents of children with developmental disabilities. From the professional viewpoint, teachers feel that shared decision-making in IEP development reduces their autonomy and increases external accountability for their teaching methods. Teachers have also reported that interactions with parents are a major source of job stress and that many teachers have negative or ambivalent feelings about the value of information provided by the parents of their students. From the parents' viewpoint, many mothers expressed the need for a rest from full-time educational responsibilities. Parents

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felt that they do have useful information to share but that the development of goals, objectives and educational methods should remain the responsibility of the teaching staff. The literature reviewed in this chapter presents parents and professionals as two groups who are not highly motivated to work together. This resistance to a collaborative relationship may be due to lack of preparation on the parts of both parents and professionals. Very little emphasis has been placed on training professionals in positive communication skills and how to engage in joint decision-making. Parents would also benefit from training concerning their legal rights and methods of participating more fully in the educational system.

Paul, J. & Porter, P. (1981). Parents of handicapped children. In J.L. Paul (Ed.), Understanding and working with parents of children with special needs (pp. 6-22). San Francisco, CA: Holt, Rinehart & Winston.

The authors provide a comprehensive review of historical literature concerning children with disabilities. Specific topics explored are: parental roles, family experiences, the educational system, parent advocacy, parent-professional alliances, and services for parents. In addition to their active role as advocates in developing or influencing services for their children, parents have become increasingly involved with professionals at the decision-making level concerning educational programming. One accomplishment of P.L. 94-142 is that it provides an instrument of accountability in the form of written individual educational programs and guarantees parents a role in making educational decisions affecting their child. Trust and mutual respect are the bases for a supportive parent-teacher relationship in which the child's interests will be best served.

Porcella, A. (1980). Increasing parent involvement. Education and training of the mentally retarded, 15(2), 155-157.

The Exceptional Child Center at Utah State University provides school services to children with severe developmental disabilities and uses parent trainers to provide a variety of home services geared toward increasing parent involvement. Children with severe emotional and physical disabilities have the greatest need for basic life skills such as communicating their needs, self-care, and toilet training. These skills are part of the school and home routines, and it is essential that children learn to function well in both environments. Families may place a request for home services and specify the need or skill to be worked on and the days and times convenient for the family to work with the parent trainer. Parent trainers may also assist families by attending staff meetings or school board meetings in an advocate/advisor role. Other methods of getting parents to increase their involvement level is for teachers to invite the parents to demonstrate successful methods of interacting with their child. Schools may also lend equipment, books, and toys for the parent to use in a home program with the child. Teachers and therapists must keep the communication line open between the school and home through regular phone calls, notes home, or parent visits to the classroom. Educating parents about their legal rights and showing them that the school supports their participation will empower parents to become more active in their child's school program.



Rosenfeld, A.H. (1979). Parents as co-therapists with autistic children. *Parent-child program series*, Report No. 3. Rockville, MD: Center for Studies of Child and Family Health, National Institute of Mental Health.

This report is part of the Parent-Child Program Series which attempts to make visible successful models of programs utilizing families in partnership with professionals. The Child Research Project at the University of North Carolina, developed by Drs. Eric Schopler and Robert J. Reichier, is described as a way to extend professionally staffed treatment programs for children with autism or communication disabilities by using the children's parents as co-therapists. The basic plan of the program includes both a treatment program and a home program. The treatment program consists of weekly therapy sessions with a child and a professional; parents and a professional parent-consultant observe the session through a one-way mirror. Daily "exercises" carried out with the parents at home comprise the home program with parents asked to demonstrate the home program exercises at regular intervals to professionals observing behind a one-way mirror. A monthly parent group meeting is also utilized for support.

Schuck, J. (1979). The parent-professional partnership-myth or reality? *Education Unlimited*, 1(4), 26-28.

The author examines whether the knowledge and experiences of parents of children with developmental disabilities are actually being used as primary resources by educators or if parent participation in the special education process is actually a new form of tokenism. Several factors are identified that account for low parent involvement including: parents have not been prepared to participate in the system; professionals' low communication skills; and professionals' lack of sensitivity toward the needs of families. There appears to be a shortage of literature and training programs for professionals to develop the skills necessary to work effectively and sensitively with the families of children with developmental disabilities. A training course for both parents and professionals is offered at the University of Minnesota that covers the topics of communication skills, family therapy, specific types of disabilities, and the role of advocates. Each student also becomes a "friendly advocate to a family with a child with special needs." Students have found that keeping a diary of their thoughts and interactions with each family member has been a highly rewarding and educational experience.

Seligman, M. & Darling, R. (1989). Professional-family interaction: Working toward partnership. Ordinary families special children (pp. 214-241). New York: Guilford Press.

The authors explore the views that professionals and parents have developed of each other through prior interactions and through media images. Characteristics associated with the professional role include traits of dominance, achievement, universalism, functional specificity, and affective neutrality. The authors stress the need for professionals to be aware of the preconceived notions that parents hold about professional roles.

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Professionals, as members of society, have been exposed to stigmatizing attitudes towards individuals with disabilities and may have more negative views of the impact of a child with disabilities on families than the families have of themselves. The clinical perspective in which professionals have been trained may have promoted negative views of individuals with disabilities and their families through a victim blaming approach. The authors emphasize the need for a social system perspective that recognizes the effect of social system values on an individual's behavior and identifies real, system-based needs such as financial aid or help with child-care rather than attributing problems with coping to parental inadequacy.

As a result of having differing life experiences, "professionals may have difficulty 'taking the role' of the parent, and parents likewise may have difficulty understanding the professional's point of view." Parents and professionals tend to play the role that they believe will achieve the desired response from the other. New roles are being created through an emergence of parent-professional partnership. The authors describe some practical exercises to improve professional role-taking ability: writing an autobiography of experiences with individuals with disabilities; getting to know someone with a disability and their family; reading personal accounts of parents of children with disabilities; and participating in disability simulation experiences. Advocacy by professionals is necessary to bring about social change to produce access, public awareness, and resources.

Shelton, T.L., Jeppson, E.S. & Johnson, B.H. (1987). Family-centered care for children with special health care needs. Washington, D.C.: Association for the Care of Children's Health.

This book is part of a project by the Association for the Care of Children's Health aimed at enhancing utilization of a family-centered approach in caring for children with special health care needs. Eight elements of family-centered care are delineated by the authors with a chapter devoted to each element: recognition of the constancy of the family in the child's life; parent/professional collaboration; sharing of complete and unbiased information between parents and professionals; provision of comprehensive emotional and financial support to families; family strengths and respect for differences in methods of coping; understanding of developmental needs of infants, children, and adolescents and their families; facilitation of parent-to-parent support; and designing systems to be flexible, accessible, and responsive to family needs. Specific projects and programs throughout the nation are highlighted that promote each of these elements. A separate chapter is devoted to a research review of selected studies focusing on family-centered care. Checklists are offered to provide direction in the implementation of this approach on various systems levels. A resource section is included with information on technical assistance and audio visual and written materials.

Silvern, J. (Ed.). (1988). Focus: Families of children with special needs. Family Resource Coalition Report, 7(2), 1-24.

This report provides a collection of articles focused on the families of children with special needs. The subjects covered range from family-centered care and the importance of

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parent/professional collaboration in treatment to discussions of newer legislation that affects the delivery of services to children with disabilities and their families. Detailed descriptions of early intervention programs in Texas, Connecticut, Washington, Ohio, and North Carolina are presented as well as a listing of literature and national organizations for the families of children with special needs.

Simons, R. (1987). After the tears: Parents talk about raising a child with a disability. *Professionals* (pp. 47-52). San Diego, CA: Harcourt Brace Jovanovich.

"Not being treated like an individual - not being listened to - is parents' greatest complaint about professionals." The author offers suggestions for parents in creating partnerships with professionals. Developing positive communication skills involves being assertive but not aggressive, promoting open communication by listening to professionals in the same manner in which one would like to be heard, and 'shopping around' to find a doctor with whom one feels comfortable. It is emphasized that the parent is the child's expert and has important assessment information to provide to professionals. Maximizing the use of professional time by preparing questions and keeping a log of particular concerns is suggested. The author stresses the parent's responsibility for making a partnership work and does not address issues of professional responsibility for collaboration.

Singer, G.H.S. & Irvin, L.K. (Eds.). (1989). Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes.

This book presents an overview of the developing field of family support services for families of individuals with developmental disabilities. Two major ideas that inform the basic organization of the book are the roles of family 'ress and the concept of the family life cycle. Stress theory is utilized to describe circumstances that weaken the adaptation capacities of families. Preventive as well as ameliorative services are promoted as a means of assisting families to cope with stressors.

Innovative family support demonstration projects are presented, designed to reduce stress by providing resources, social support, improved perceptions of individuals with disabilities, coping skills, strategies for parent-professional collaboration, and contact with other families. Evaluation results on these projects are presented along with policy implications.

The theme of parent-professional partnerships is emphasized throughout the book. A variety of strategies for improving collaboration is suggested by contributing authors including: offering parents a choice of roles; emphasizing the importance of cooperative professional values and empathetic communication styles; assisting parents in ways that enhance their feelings of competence; and encouraging parents to set their own goals.

A separate abstract is included in this bibliography for chapter seven (Walker, 1989).



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Turnbull, A.P. & Turnbull, H.R. III (1986). Families, professionals, and exceptionality: A special partnership. Columbus, OH: Merrill Publishing Company.

The focus of this book is on improving the effectiveness with which professionals, families, and people who are exceptional work together. Exceptionality broadly encompasses all types of disability and giftedness. People who are exceptional are viewed as having similar characteristics of how they are affected by relationships with families and professionals although differences due to the type and extent of exceptionality are also addressed. The authors utilize a family systems approach, examining the context of exceptionality across the life cycle without being bound by a focus on the member who is exceptional. The diversity and uniqueness of family systems are recognized. Professional support to promote maintenance of family balance is emphasized. The authors wrote the book with an interdisciplinary orientation in an attempt to be useful to a wide range of professionals, including those working in special education, social welfare, psychology, counseling, and health. The personal stories of families are utilized to ground the theories and concepts in the reality of family life.

The book begins with a history of parental roles in exceptionalities. Family systems concepts are presented in four chapters focusing on family resources, family interactions, family functions, and the family life cycle. The next two chapters tie these concepts into parent-professional communication skills. The following four chapters discuss the legal framework of the educational system with regards to exceptionality. Providing information and support to families is the topic of the next two chapters. The book concludes with a chapter devoted to ethical and moral issues in family and professional relationships.

Warren, R.D. (1984). REACH for a difference--in the way you live: Guidelines for disabled adolescents. Rehabilitation Literature, 45(9-10), 274-280.

The author proposes a community housing program for adolescents with disabilities. Community housing programs are usually geared toward adults, yet it is stressed that preparation for individuals with disabilities should begin during adolescence. The collaboration of the family, community and teenager should be encouraged to encompass the goals of the REACH Program, which includes the following components: relationships with family, friends, and self; expectations that community living is a goal; accessibility, both architectural and attitudinal; counseling in skills necessary to manage their home; and housing options. Using the guideposts of this program, communities can pioneer efforts to allow teenagers with disabilities and their families to experience a normal transition into adulthood.

Wikler, L., Wasow, M. & Hatfield, E. (1983). Seeking strengths in families of developmentally disabled children. Social Work, 28(4), 313-315.

Clinical interventions and research with the families of children with developmental disabilities have consistently focused on the problems, stresses, and inadequacies of these families. This approach is detrimental because family strengths and successes tend to be

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overlooked, and professionals may create a negative atmosphere through low expectations of the family's abilities to cope. The authors reexamine data from their 1981 study of parents of children with developmental disabilities and the presence of "chronic sorrow" sadness that did not disappear over time - in the parents of these children. Previously unreported portions of the study examined whether parents felt that raising a child with a developmental disability had made them a stronger or weaker person. Although most of the parents reported feeling "chronic sorrow" this did not exclude parents from feeling that they were stronger people because of their experiences with their child. The authors also interviewed workers in a social service agency about their perceptions of how parents adjust to having a child with a developmental disability. Workers were accurate in their statements conce ning the amount of parents who felt "chronic sorrow," yet they greatly underestimated the extent to which parents felt strengthened by their experiences and the extent to which parents wanted to be encouraged to be strong and develop new methods of coping. The parents' motivation to be successful and care for their child with a disability was much higher than the workers assumed. The authors recommend focusing family research on the positive aspects of raising children with developmental disabilities and closer examination of the factors that reduce family stress and increase feelings of support and strength in the family system.

Zirpoli, T.J., Wieck, C. & McBride, M. (1989). Case management: A new challenge for families. In M.H. Linz, P. McAnally, & C. Wieck (Eds.), Case management perspectives: Historical, current and future. Cambridge, MA: Brookline Books.

The authors discuss the concept of parents functioning as case managers for their children with developmental disabilities. The natural role of parents uniquely satisfies several of the criteria for selection of a case manager: high intensity of involvement, coordination of services, family preference, and accessibility to the family. In order to develop the ability to obtain appropriate services for their children, parents need training in service availability, legal rights regarding acquisition of services, and advocacy skills. The authors describe two educational programs, Parent Case Management (PCM) and Partners in Policymaking (Partners), based in Minnesota that are designed to provide parents with the knowledge and skills required of parent case managers. Research evaluating the effectiveness of these programs is presented. In the Parent Case Management project parents were paired with public county case managers; research results indicated that the children received more services, parents felt more empowered, and the county case managers reported a more cooperative working relationship with parents. Partners in Policymaking has resulted in significantly greater advocacy involvement by professionals on behalf of parents.



## **EARLY INTERVENTION**



Dunst, C.J. (1988). Supporting and strengthening families: New visions, new directions. Family Resource Coalition Report, 7(2), 4-5.

The author compares three federal documents and the various ways that Public Law 99-457 can reshape family support services. Public Law 99-457, passed in October 1986, amended the Education of the Handicapped Act to include an early intervention program for infants and toddlers with disabilities and their families.

The needs statements found in federal documents tend to fall into three categories: traditional child-focused perspective; family involvement perspective; and broad-based family-focused perspective. The child-focused perspective of early intervention places emphasis on the child's needs and is implemented through educational or therapeutic interventions. The family involvement perspective addresses family needs but only those needs related to enhancing the development of the child with a disability. Finally, the broad-based family-focused perspective attempts to address the children's needs, the needs of other family members, and the family unit itself. Although the last approach seems to hold the most promise for new effective services to children and families, many professionals are not supportive of this perspective due to the belief that there are not enough staff or resources to provide services to everyone in need.

The author reframes this interpretation of broad-based family-focused treatment by stating that early intervention programs should "assist" families in accessing resources. Professionals should engage in practices that enable and empower families to effectively state their needs and mobilize resources to meet those needs. Studies have found that intervention efficacy is highest if the family and the professional agree on the needs to be addressed. Public Law 99-457 provides an opportunity for professionals to influence and support broad-based efforts in services to children and families.

Dunst, C.J. & Trivette, C.M. (1988). A family systems model of early intervention with handicapped and developmentally at-risk children. In D.R. Powell (Ed.), Parent education as early childhood intervention (pp. 131-180). Norwood, NJ: Ablex.

The authors present a model of family functioning developed on a social systems framework. Research data from a series of eight cross-sectional studies are summarized in relation to the social systems model and are consistent with the predicted direct and indirect influences of social support: "support affects well-being which in turn affects interactional styles which in turn influences child behavior."

Theory is then applied to practice at the Family Infant and Preschool Program (FIPP) in North Carolina. Early intervention is redefined from a systems orientation to broaden provision of support to include both informal and formal social support networks. Intervention is guided by a philosophical orientation emphasizing family enablement and empowerment based upon the PEP (Proactive Empowerment through Partnership) model. The PEP model emphasizes identifying and strengthening child and family capabilities using a proactive rather than a deficit approach, enabling and empowering parents through knowledge, skills, and resources, and using partnership between parents and professionals as the means to strengthen, enable, and empower families. A needs-based approach to assessment and intervention is utilized with family-identified needs taking precedence over

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professional-identified needs. Social networks are viewed as a primary source of meeting needs. Emphasis is placed on mobilizing informal support networks at the level closest to the family.

Dunst, C.J. Trivette, C.M., & Deal, A.G. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

This book is written to provide early intervention practitioners with information on family systems assessment and intervention procedures. The authors suggest rethinking intervention practices to include a social systems perspective with a focus on the family. Empowerment of families is emphasized through building on the family's personal social network as a primary source of support. A proactive stance that stresses positive growth is important as is a commitment to family identified needs. A change is needed in the way professional roles are performed through the development of partnerships with family members.

A model is presented utilizing four operational components. First, family needs and aspirations are assessed. Second, intrafamily strengths and capabilities are identified. Third, the family's personal support and resource network is "mapped." And fourth, help-giving behavior (professional roles) are utilized to help families mobilize resources to meet their needs.

Healy, A., Keesee, P.D. & Smith B.S. (1989). Parent-professional interactions. Early services for children with special needs: Transactions for family support (Second Edition) (pp. 41-64). Baltimore, MD: Paul H. Brookes.

The authors examine parent-professional interactions in the field of early intervention, asking: "How can professionals contribute their expertise and assistance in ways that will respect the family's integrity as well as promote competence and independence in both parents and child?" Parent competence is chaitenged by the birth of a child with disabilities - an event which is not in the parent's control. It is important for professionals to find a balance between providing support to families and promoting the competence of the parents. This is a developmental process in that needed support at one time may lead to dependency if parental competence is not emphasized. In promoting parental competency it is essential to determine when decision-making requires professional expertise and when parents are singularly most competent to make decisions on their child's behalf.

Unrealistic expectations by professionals regarding the therapeutic regime are addressed, as well as professional socioeconomic and cultural biases. Difficulties in communication between professionals and parents may result from differences in definition of terms or undefined and vague terms. The lack of agreement among various professionals and the focus on the child's deficits to the exclusion of strengths are additional sources of tension between parents and professionals. Communication is described as the key to improved

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parent-professional interactions. Communication can be aided by minimizing or translating technical language and jargon, including written materials to supplement verbal discussions, acknowledging the unknowns, and providing information on other resources. Throughout this chapter the authors describe how Public Law 99-457 has supported improved parent-professional interactions.

M.J.S. & S.D.K. (1990). Editorial: Parents and professionals. Exceptional Parent, 20(3), 48.

The focus of this editorial is the relationship between parents and professionals and the concern that parents may shy away from early intervention programs based upon the negative experiences of other parents. Special education has changed drastically in the past few years such that parents have the right and obligation to evaluate early intervention programs. This is a dramatic shift from twenty years ago when parents had to compete for school slots for their children and often families needed to relocate in order to receive the services that their child needed. The goal of this publication is to help parents become informed consumers when searching for services for their children. On the side of professionals it is important that they learn more about families, and methods of working cooperatively with all types of parents. Professionals must remember that parents have a range of family, vocational and personal responsibilities in addition to caring for their child with a disability.

Peterson, N.L. & Cooper, C.S. (1989). Parent education and involvement in early intervention programs for handicapped children: A different perspective on parent needs and the parent-professional relationships. In M.J. Fine (Ed.), The second handbook on parent education: Contemporary perspectives (pp. 197-234). San Diego, CA: Academic Press.

The authors begin this chapter with a brief r view of the legal history of early intervention programs. The crucial nature of the parents' role in early intervention is elaborated: their significance in providing stimulation and opportunities for their child; their potential to be key intervention agents; the promotion of a positive perspective on the child's disability and their position as parents as a result of their involvement; and associated economic benefits.

The authors discuss the kinds of professional assistance that parents have described as congruent with their needs. Parents need information about their child's disability and about local resources. They need an informed professional partner for mutual problem solving and a support network. Parents need the training to acquire any special skills required to meet their child's special needs. They also need time off from their parenting demands. The parents consulted by these authors spoke of valuing informal and open, two-way communication with professionals. They wanted the opportunity to engage with the professionals in frequent face-to-face contact and to observe them working with their children. Parents want to be respected as primary decision-makers regarding their child's treatment. Professional preparedness for working with parents demands "process skills" in facilitating open communication.

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Radin, N. (1990). A new arena for school social work practice: At-risk infants and toddlers. Social Work in Education, 12(4), 275-282.

The author discusses Part H of Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, and emphasizes the potential for involvement by school social workers. In accordance with Part H of P.L. 99-457, children from birth until their third birthday are eligible for early intervention services if they are developmentally delayed or at risk of developmental delay (at state discretion). Part H stipulates that for each eligible child an assessment and an Individualized Family Service Plan (IFSP) be developed by a multidisciplinary team including the child's parents. Parents are considered as team members rather than clients under the orientation of Part H. The IFSP is required to contain a statement regarding the family's strengths and needs.

The applicability of the professional training of social workers is stressed in terms of the skills of family and environmental assessment. Resources to provide an enriched knowledge base about IFSPs and P.L. 99-457 are offered.

Two obstacles to school social workers participation on IFSP committees are explored. The first obstacle is a lack of training in normal infant development and conditions associated with developmental delay such as fetal alcohol syndrome, rubella, human immunodeficiency virus infection, and spina bifida. Workshops, courses, and training programs are suggested with some specific programs mentioned.

The second obstacle is the tendency to view parents of children at risk for development delay as clients rather than partners. Use of a transdisciplinary model of team interaction in which families play a central role as full team members is recommended. The authors articulate the necessity of service goals to reflect priorities and values of the family, rather than of the staff, in terms of ethics, parental rights, pragmatism, and the reality that parental needs will guide behavior.

Weil, M., Zipper, I.N. & Rounds, K. (1990). Parent/professional partnerships in case management. Case management for early intervention programs: Parent & professionals (pp. 51-59). Carolina Institute for Research on Infant Personnel Preparation, Frank Porter Graham Child Development Center.

The authors discuss how case managers in early intervention programs under P.L. 99-457 can develop successful parent/professional partnerships. It is emphasized that case managers must respect the families' ultimate authority in decision-making. An effective parent/professional partnership utilizes mutual problem solving to establish goals and plan interventions. The case manager acts to empower parents with the abilities to participate as full partners so that parents feel increasingly competent to assume case management responsibility over time.

Challenges to creating parent/professional partnerships are described and include: early intervention professionals' lack of training and experience in working with families; communication difficulties due to professional jargon; acceptance of professionals assuming an "expert" role; cultural, ethnic, and value differences; and systemic constraints such as scheduling conflicts, transportation difficulties, caseload sizes, and lack of financial resources and available services. The critical importance of the process of developing and

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Individualized Family Service Plan (IFSP) is stressed in the creation of expectations that shape the future relationship between parents and professionals.

Winton, P.J. (1988). Effective communication between parents and professionals. In D.B. Bailey, Jr. & R.J. Simeonsson (Eds.), Family assessment in early intervention (pp. 207-221). Columbus, OH: Merrill Publishing Company.

The authors stress the importance of parent/ professional collaboration in formulating effective individualized plans for children with disabilities. The attitudinal, perceptual, and cultural barriers that can hinder communication between families and professionals are discussed, as well as a family's receptivity to intervention efforts. Interviewing techniques that are necessary for clear communication are presented in terms of effective listening and questioning skills. These skills are essential not only in focused interviews, but in continued interactions with the family members of a child with a disability.

Winton, P.J. & Bailey, D.B.Jr. (1988). The family-focused interview: A collaborative mechanism for family assessment and goal-setting. *Journal of the Division for Early Childhood*, 12(3), 195-207.

The authors describe four assumptions which ground the work with families in early intervention: 1) each family is unique; 2) family needs are developmental; 3) family-focus involves focusing on the needs of all family members; and 4) the social environment in which the family is embedded must also be considered. These assumptions have been integrated in a model for early intervention services referred to as Family-Focused Intervention. "The model emphasizes collaborative goal-setting with family members and consists of six steps: assessing family needs, generating initial hypotheses regarding family needs, conducting a focused interview, formalizing a plan providing services, and evaluating effectiveness." This article provides a rationale and description for the family-focused interview, a component of this model.

The structure of the interview is detailed and specific communication skills are discussed. Research evidence documenting the effectiveness of the interview in assessing family needs and developing goals is presented. The family-focused interview is viewed as a single piece of a broader intervention model that includes a broadened role for the early interventionist as case manager as well as child specialist. It is emphasized that while the interventionist's role is to collaborate with the family in setting priorities, identifying resources and supports, and providing assistance in problem solving, the family itself holds the most adequate solutions to problems within their definition of reality.

Zeanah, C.H. & McDonough, S. (1989). Clinical approaches to families in early intervention. Seminars in Perinatology, 13(6), 513-522.

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The authors describe the movement to design early intervention treatment plans which focus on the individualized needs of families in accordance with the passage of Public Law 99-457. The need for early interventionists to understand the contributions of early experiences on family's expectations of their child's development is emphasized, and information regarding psychological aspects of pregnancy, prematurity, full-term disabling conditions, and psychosocial family risk factors are presented. The working alliance is proposed as a model for parent-professional relationships. Five clinical principles are described as essential to developing and maintaining a successful working alliance: sensitivity to the family's unique situation, responsivity to the family's needs, positive connotation of infant and parent behavior, a nonjudgemental attitude, and a willingness to monitor intense feelings aroused by the family.



## **EDUCATIONAL SYSTEM**



Bernard van Leer Foundation (1986, May). The parent as prime educator: Changing patterns of parenthood. Summary report and conclusions, Fourth Western Hemisphere Seminar, Lima, Peru.

This article presents a summary of the conclusions of the Fourth Western Hemisphere Seminar on the situation of the young child and family in Latin America. This seminar in Lima, Peru was attended by representatives of 18 countries as well as major international organizations. An informal system of preschool education is suggested in which the professional takes a role of facilitator rather than teacher in bringing together parents in the community to promote parent roles as educators. Improving the self-esteem of parents by empowering them as valuable educators as well as increasing social contact and communication with other community members is emphasized.

In Latin America, the involvement of fathers in education and caregiving of children has been minimal. There is a need in early education to work with fathers to enrich their role in providing positive role models for children. Local community programs should promote cultural awareness; providing a strong foundation in the child's own culture will allow for the later development of mastery in new skills and languages.

The relationship of parents and professionals or para-professionals should be complementary, not hierarchical. The role of the professional is to help parents systematize their experiences, develop common meeting ground with other parents, enrich their environment, and collaboratively develop teaching-learning situations for their children.

It is concluded that at this educational stage a good curriculum is one that is family based as well as supportive of the family, allowing the hild to develop a stable socialization foundation from which to explore other environments.

Bloch, J.S. & Seitz, M. (1989). Parents as assessors of children: A collaborative approach to helping. Social Work in Education, 11(4), 226-244.

The authors present a home-school collaborative approach in the assessment of preschoolers with special needs. This method provides a new role for parents as equal participants in the assessment process. The instrument used is The 5 Ps (Parent/ Professional Preschool Performance Profile), which rates the child's observed performance in two primary natural settings -- the home and the school. Completion of the ratings is the combined responsibility of both parents and teachers. The ratings include measurements of developmental skills and specific behaviors. The 5 Ps is designed to be used with children ranging in age from 6 to 60 months and is organized in a developmental hierarchy which lists competencies based upon age. Parents are trained by school and social work staff, and measures of reliability and validity have found that correlations between teacher and parent ratings are very strong. Research has been expanded to ten schools and data are being collected on 400 students. The study in progress will also examine the judgments of parents and teachers regarding the success and feasibility of this collaborative method.



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Brinckerhoff, J. & Vincent, L. (1986). Increasing parental decision-making at their child's Individualized Educational Program meeting. Journal of the Division for Early Childhood, 11(1), 46-58.

The legal mandate of parent participation in the IEP decision-making process may be interpreted differently by parents and school staff. In order to develop ways for schools to improve parent participation in IEP meetings, a training package was developed for both parents and professionals. Fourteen families of children with disabilities participated. The parents in the experimental group completed a developmental assessment of their child's current level of functioning, completed a family profile, and met with a school liaison person prior to the IEP meeting. Parents in the control group received only a letter stating the purpose and time of the IEP meeting. Tapes of the IEP meetings were coded and analyzed.

It was found that parents from the experimental group had a significantly greater frequency in contributions, goals generated, and programming decisions made at IEP meetings. In addition school staff were more responsive to parents from this group and provided more home programming suggestions to these parents. Parents from both groups reported a high level of satisfaction with their child's IEP meeting on a follow-up questionnaire.

The significantly greater participation level in the experimental group may be attributed to the following factors: the experimental group parents collected information on their child in a goal directed and meaningful manner; the parent-generated information was matched to the school staff format; the parents had hands-on experience in assessment in their home environment; and the parents had additional meetings with a liaison from the school.

D'Zamko, M. & Raiser, L. (1981). IEP development and implementation: Systemic parent-teacher collaboration. *Teaching Exceptional Children*, 13(3), 122-124.

The authors describe a model for parent-teacher collaboration in the IEP process which requires minimal time and effort from of both parents and teachers. This systemic approach involves parents in three phases of the child's IEP: assessment, development, and implementation. Special education team members can provide parents with a list of questions to guide their observations of the child in the home during the weeks prior to the IEP team meeting. Following the home observations of the child's activities, the parent is prepared to become an active participant during team meetings. Once long term and short term goals are identified the parent can supplement the child's education informally in the home environment. These activities are designed to complement school learning and are not time consuming in nature. Parents may use readily available tools that are found in any home (cereal boxes, soup cans, newspapers, magazines), and this technique is applicable to any school subject. Monitoring of this collaborative model can be done through periodic parent-teacher conferences to discuss the child's progress.



Gilliam, J.E. & Coleman, M.C. (1981). Who influences IEP committee decisions? Exceptional Children, 47(8), 642-644.

A study was conducted to examine the roles of IEP committee members. The study was designed to determine which roles are perceived as most important to the process, who is most influential in decisions, and who contributed most to decisions reached. Data were obtained from 199 people who participated in IEP committees including parents, teachers, psychologists, speech therapists, and administrators. Prior to IEP meetings each person ranked the importance of differing roles in IEP formulation. After the meeting, each member was asked to rate themselves and others considering their influence and contributions to diagnosis, planning, placement, and implementation. Although parents were expected to have an important influence on the IEP process, responses on the survey showed that parents were perceived as low in actual contribution. In response to the results from this survey, the authors made three recommendations for improving the IEP process. The use of a concise and explicit data sharing form would increase communication between specialists. It was also suggested that case managers be used to organize meetings and be responsible for paperwork, sharing and exchange of information. Parents need to be more fully involved, especially in the assessment and data gathering phases of IEP development, such as evaluating the child's performance of activities outside the school environment.

Hains, A.H., Fowler, S.A. & Chandler, L.K. (1988). Planning school transitions: Family and professional collaboration. *Journal of the Division for Early Childhood*, 12(2), 108-113.

The authors address some of the key issues involved in planning transitions for young children who are moving from special education preschool programs to mainstreamed kindergarten placements. The role of the educational agencies is to ensure good communication between the sending and receiving programs in which the child participates. This collaborative planning will enable a smooth transition for the child and continuity of services. The sending teacher must determine what skills are needed by the child and then demonstrate that the child is indeed ready for a less restrictive environment. The receiving teacher must be prepared to accommodate the child and adapt teaching methods to meet the child's needs. The family's role is to alter their routine and prepare the child for new behaviors, experiences and expectations. Parents may also participate in the transition by identifying their concerns, choosing their level of involvement, and accessing information or strategies that may assist in the change process. Parents may function as teachers by helping their child practice at home some of the skills acquired in preschool. The process of transitioning a child to a new school program is complex and requires good communication and dedication from all the individuals involved.

Hamre-Nietupski, S., Krajewski, L., Nietupski, J., Ostercamp, D., Scnsor, K. & Opheim, B. (1988). Parent/professional partnerships in advocacy: Developing integrated options within resistive systems. *Journal of the Association for Persons with Severe Handicaps*, 13(4), 251-259.

The authors discuss the need for continued advocacy efforts to promote integrated

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education options for children with disabilities within resistive school districts. The benefits of parent/professional partnerships in advocacy are highlighted. Parents offer the advocacy partnership a strong commitment to their children, an intimate knowledge of their children's needs, and an ability to influence the community through networking with other parents. Professionals can add experience with "the system," knowledge of professional literature to support the feasibility of integration, and expertise in how to make integration work.

Specific strategies are presented for securing integrated options based on the personal experiences of the authors as members of a parent/professional advocacy group. In accordance with the partnership emphasis, parents are advised to bring their own advocates - other parents or professionals informed of legal rights and integration issues - to I.E.P. conferences and placement staffings. Training on conflict resolution is suggested for future parent/professional programs. "Parents need to know that it is 'okay' to disagree with professionals and should be taught strategies for successfully presenting their disagreements."

Hauser-Cram, P., O'Leary, K.M. & Spar, A. (1981, April). Parents and schools: A partnership model. Paper presented at the Annual Meeting of the American Educational Research Association, Los Angeles, California.

The authors describe Project Partnership in Massachusetts, a program that seeks to promote parent/professional collaboration in the education of young children with special needs. It is assumed that all participants stand to benefit from parent/professional collaboration: the children with improved school performance and IQ, the parents with enhanced parental competence and efficacy, and the teachers with increased availability of information about the children.

Project Partnership is described as an approach rather than a distinct model. The beginning component is a series of workshops offered for teams of parents, teachers, and administrators that provide training in communication skills and collaborative strategies. A core component of the program is the position of Parent Coordinator, a parent who bridges the gap between parents and educators by functioning as a liaison to other parents, helping to organize parent-teacher activities, conducting parent groups, and providing guided observations of the classroom. Additional functions of the Parent Coordinator with special needs children include co-leading groups with teachers on effective parenting and living with a special needs child. A small stipend is provided to the Parent Coordinator to help defray transportation and babysitting costs and to show the parent's that their time is valued. An additional key component of Project Partnership is the mini-grant \$400 maximum provided to each team on the basis of a proposal for beginning or continuing development of a parent program in their own setting.

An evaluation completed at the end of the first year of the project showed a significantly higher number of parent-teacher contacts for the group in Project Partnership compared to the control classroom with greater initiation of contact by parents, rather than teachers.

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Jones, B. (1989). Parents as partners. New Ways, Winter, 16.

The author identifies the key elements to effective parent/professional collaboration in the educational system. Parents and professionals must be accepting of the roles and opinions of other team members, and use these differences as a positive catalyst for change. Participants need to be honest and direct in their communication and develop good listening and questioning skills in order to thoroughly understand each team member's perspective. A difficult part of collaborative efforts is the need to negotiate and compromise. A "workable compromise" allows both parents and professionals to retain the integrity of their opinions, without asking for one side to make large alterations in goals while the other side gives up very little. Parents become effective participants through knowledge of the special education process, and their involvement in school board meetings and advisory committees can influence changes in the educational system.

Jones, B. (1989). Parents as professionals. New Ways, Winter, 18-19.

The author describes the growth and development of Parent Training and Information Programs (PTIs) across the United States. "The mandate for PTI programs like PEAK (Parent Education and Assistance for Kids) is to provide training and information to parents of handicapped children and volunteers who work with parents to enable such individuals to participate more effectively with professionals in meeting the educational needs of handicapped children." PTI programs also aim to integrate families more fully with the community, emphasize family support systems, and shift professional attention from family weaknesses to strengths. Included is a description of Oregon PTI Programs.

Leyser, Y. (1988). Let's listen to the consumer: The voice of parents of exceptional children. *The School Counselor*, 35(5), 363-369.

In response to the movement toward collaboration between home and school occurring both theoretically and as a result of legal mandate (Education for All Handicapped Children Act of 1975), a survey was conducted with parents of children with disabilities to obtain information regarding their needs, concerns, and desires. A sizable number of parents were found to attend few, if any, school conferences. Comments made by these parents indicated that they perceived the information provided as being primarily negative and felt left out of the decision-making process. Inflexible scheduling of school meetings during daytime hours and difficulty with transportation were identified as problems in regards to attendance. Fifteen to 20% of the parents described school conferences as not useful. Many respondents indicated a desire to be informed about the curriculum and suggested sharing information through channels alternative to conferences such as notes sent home, progress reports, and newsletters. Interest was expressed in education and training on home teaching strategies, legal rights, community resources, and behavior management skills. One third of the parents were interested in counseling.

The authors emphasize that these results reinforce the concept of the heterogeneity of parents of children with disabilities and recommend the matching of programs to the

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unique needs and interests of parents. The implications for school counselors are explored. Suggestions are offered for redefining the role of school counselors to provide training for teachers on how to work effectively with parents and training to parents on topics of expressed interest as well as direct service or referrals to appropriate agencies.

Lipsky, D.K. (1989). The roles of parents. In D.K. Lipsky & A. Gartner (Eds.), Beyond separate education: Quality education for all (pp. 159-179). Baltimore, MD: Paul H. Brookes.

The author warns against labeling parents of children with disabilities as "disabled parents" and then applying a model of pathology to understanding parents' reactions. Instead of exclusively viewing the parents' reactions through an intrapsychic lens, their reactions also may be seen as rational responses to societal factors such as inadequate services, lack of social and economic supports, and professional ignorance. Changing family life patterns and cultural differences create unique situations for each family. Family needs differ throughout the life cycle much as do the needs of families with children who are not disabled.

Involvement of parents in the IEP process through the legal requirements of P.L. 94-142 was initially intended as a means of protection and advocacy for the interests of children with disabilities. The limited actual involvement of parents in the IEP process that has resulted may be due to such factors as: (1) lack of desire to participate; (2) inability to participate; and (3) perception of being unwelcomed by the school. Parents may feel unwelcomed by the schools due to school professionals' lack of training in working with adults, or school professionals may be responding to the parents as a challenge to their professional expertise.

The concept of family support and characterizes effective family support as consisting of early initiation, integrated services, universal access, ability to address the family's unique set of needs, individualization to fit family members' unique needs, strength rather than deficit perspective, mutual support among families, and priority given to meeting the wishes of the family. The concept of parent-professional partnership is addressed and is described as being "built on professional accountability to parents. It includes mutual respect, sharing in a common purpose, joint decision-making, sharing feelings, and flexibility in dealing with each other."

Pennekamp, M. & Freeman, E.M. (1988). Toward a partnership perspective: Schools, families, and school social workers. Social Work in Education, 10(4), 246-259.

The ecological perspective is utilized to examine the microsystem, mezosystem, exosystem, and macrosystem of the interaction of families, schools, and communities. Barriers to family-school partnership are explored from the position of the family, who may be mystified by school processes; from the school staff, who may not have been trained in this capacity; and from the community, who may lack awareness of families' needs. Power and status issues affecting collaboration between professionals is discussed. Suggestions for

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overcoming barriers to family-school participation are offered and include: family-school needs assessment, parent orientation, parent ombudspersons, training school personnel, coalitions with allied groups, and joining community-based providers. The authors describe the emergence of new themes through development of family-school partnership: joining among stakeholders, using anticipatory guidance to enhance competence, and fostering hope.

Schulz, J.B. (1987). The parents' role in special education. Parents and professionals in special education (pp. 89-108). Boston, MA: Allyn and Bacon.

Over the last forty years, the parents' role in services to children with disabilities has moved from that of sole provider to passive recipient, and finally in recent times to equal participant. In the middle of the twentieth century many children with disabilities were excluded from public education, thus parents needed to organize and finance special classes for their children. In the 1960s, the public became more accepting and aware of individuals with disabilities and federally funded programs established classes for exceptional children. Only during the last decade has national attention focused on the importance of parents as a part of the educational planning team. The authors examine the growth of parent advocacy since the 1940s, and the parents' role to represent the interests of their children and ensure that the school systems provide the appropriate educational environment. In addition to child advocacy, parent organizations have provided mutual aid and comfort to families with similar obstacles and influenced litigation to bring about broader social change. Although PL 94-142 established parents' rights to participate in the educational system, large discrepancies exist between the ideals of parent participation and the actual practice. Most parents are involved in a passive manner, such that they read and sign their child's IEP each year. Ideally, parents should participate in generating interventions and program plans for their children, evaluating those plans, and finally selecting the appropriate solutions. This type of participation requires a serious commitment from the parents. Not all parents are able to be involved at this level due to time constraints. complex family situations, and cultural or language barriers. It is concluded that parents should be involved as much as they want to be, and that schools should develop a comprehensive program for making parent participation a reality.

Simpson, R.L. & Fiedler, C.R. (1989). Parent participation in Individualized Educational Program (IEP) conferences: A case of individualization. In M.J. Fine (Ed.), The second handbook on parent education: Contemporary perspectives (pp. 145-171). San Diego, CA: Academic Press.

The authors begin this chapter with a brief history of the development of parent IEP involvement. The initial impetus is described as a result of advocacy by parent organizations. The significance of the enactment of P.L. 97-142, The Education for All Handicapped Children Act, in shaping current parent roles is detailed. The authors then present a rationale for individualizing parent involvement that is based on three major assumptions: (1) families have unique levels of interest and abilities; (2) educational policies should encourage a range of parent involvement options that are matched to each

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family; and (3) more involvement is not necessarily better involvement. The level of family involvement is influenced by diverse aspects of family structure such as family membership characteristics, extrafamilial support, cultural and ideological factors, coping strategies, socioeconomic status, and family life-cycle considerations. Seven levels of involvement are suggested to be used as a framework in assisting families to select their preferred degree of involvement. Two major factors to be considered in determining the appropriate level of involvement for each unique family are: (1) parent and family needs and (2) parents' preferred level of involvement. Information and assistance to move from one level to another through time as the family life cycle changes must be available. The authors describe four interpersonal factors that are necessary to establish cooperative parent-educator relationships: (a) willingness to listen; (b) trust; (c) acceptance of individual values; and (d) willingness to accommodate a partnership relationship.

Walker, B. (1989). Strategies for improving parent-professional cooperation. In G.H.S. Singer & L.K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability (pp. 103-119). Baltimore, MD: Paul H. Brookes.

The author describes a model demonstration project designed to encourage the use of cooperative strategies in the interactions of special education teachers and parents of severely disabled children. Eight teachers and 37 parents participated in the project. A trained interventionist facilitated sessions with parent and teacher that focused on the rationale for cooperation and provided specific intervention activities. The acquisition of three specific types of skills for increasing cooperation in relationships was emphasized: (1) perspective taking - understanding and appreciating the other's position; (2) positive reinforcement; and (3) maintaining frequent contact. Role play activities and written forms were used to enhance communication.

Evaluation of the model demonstration project revealed success in increasing positive perceptions of the benefits of parent-teacher cooperation and the importance of communication between parent and teachers in planning services for children with disabilities. No statistically significant impact on specific communication behaviors was found, but individual cases of cooperative settlement of disputes was observed.

Encouragement is offered by the author for future directions in research, development of public policy, and training in direct service practice settings to promote cooperation in parent-teacher relationships.



# **ADVOCACY**

Corp, C. & Kosinski, P. (1990). Parent Involved Network, Delaware County, Pennsylvania chapter: A self-help, advocacy, information and training resource for parents of children with serious emotional problems. In A. Algarin & R.M. Friedman (Eds.), Proceedings of the third annual conference. A system of care for children's mental health: Building a research base (pp. 239-245). Tampa, FL: Research and Training Center for Children's Mental Health, Florida Mental Health Institute.

Parents Involved Network (PIN) of Delaware County, Pennsylvania is a self-help group organized and run solely by parents of children with serious emotional disorders. PIN's objectives are: "1) to enhance parent/professional collaboration; 2) to increase parents' ability and effectiveness in negotiating the child-serving systems to obtain the most beneficial service for their child; 3) to reduce the isolation, guilt, frustration, and anger felt by parents; 4) to increase parent participation in the development of programs and policies relating to children with serious emotional problems." This article examines PIN's effectiveness in meeting these objectives.

Key characteristics of the PIN project that have contributed to its accomplishments are humor, empowerment of parents, peer support, education of parents and professionals, flexibility, parent/professional collaboration, and support from the child-serving systems. Professional characteristics necessary for the success of parent self-help groups include: not feeling threatened by parents seeking help from other parents; not perceiving one's professional status as a designation of sole authority to assist the family; and an ability to view parents as part of the solution rather than as the problem.

Dane, E. (1985). Professional and lay advocacy in the education of handicapped children. Social Work, 30(6), 505-510.

The focus of this article is to define and elaborate on two systems of child advocacy - advocacy efforts of parents and family members as separate and unique from advocacy effforts of social service professionals. Familiarity with the key characteristics of the families of children with disabilities is helpful to clarify what the family and the professional can offer in collaborative efforts to invoke social change and access needed services. A primary step toward beneficial exchange and support is the establishment of a non-adversarial relationship between parents and social workers. Parents of children with disabilities have a unique set of strengths and vulnerabilities including parental expertise, conflicting needs of the child and family, and risk of dysfunction in siblings. The author utilizes social exchange theory through recognition of the differential rewards and costs to each party in the parent/professional relationship in explaining how the current service system works. Methods of improving communication and services are explored.

Darling, R.B. (1988). Parental entrepreneurship: A consumerist response to professional dominance. Journal of Social Issues, 44(1), 141-158.

The author examines the growth of activism, or parental entrepreneurship, among parents of children with disabilities. Parental responses to the mental health system suggest that there are

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conditions and situational factors that influence parents to become activists for their children. Parental entrepreneurship is a response to the community's failure to provide sufficient or appropriate services for children. The specific activities involved are seeking information in a thorough manner, taking control over which services and resources are used for the child, and challenging authority figures. The parent activist role is nurtured through interactions with other parents of children with disabilities and may lead to a changed way of life for these families.

Friesen, B.J. (1989). Parents as advocates for children and adolescents with serious emotional handicaps: Issues and directions. In R.M. Friedman, A.J. Duchnowski & E.L. Henderson (Eds.), Advocacy on behalf of children with serious emotional problems (pp. 28-44). Springfield, IL: Charles C. Thomas.

The author describes parents as potentially the most powerful advocates on behalf of their children due to sustained motivation and an emotional investment in the Juture. The apparent lag in organizing parent advocacy for children with serious emotional disorders in comparison to parents of children with other disabilities is examined. An advocacy framework is outlined with four areas of concern that parents might focus on: (1) the child with serious emotional disturbance; (2) the need of family members; (3) local issues; and (4) broader system issues. According to this framework, it is only after the needs of the parents and their own children have been addressed that additional levels of advocacy involvement becomes practical.

Strategies used successfully to increase parent involvement in advocacy efforts are presented. Methods suggested by the author to enhance parent involvement include: opportunities for parents to interact with others in similar circumstances; activities that acknowledge parental expertise in relation to their child and allow parents to contribute in meaningful ways; programs designed to train and utilize parents in educational or therapeutic roles; and inclusion of parents as members of boards, advisory committees, task forces, etc. Three types of dilemmas that professionals may encounter in facilitating parent involvement are presented to aid professionals in anticipating and preparing for these problems: (1) parents' anger at the system directed toward professionals as symbols of the system; (2) differences in goals or in the means to achieving goals between parents and professionals; and (3) differing and conflicting objectives between parents themselves as a heterogeneous group.

Friesen, B.J., & Huff, B. (1990). Parents and professionals as advocacy partners. *Preventing School Failure*, 34(3), 31-36.

Parents' effectiveness as advocates for their children is discussed in terms of their constancy, their emotional investment, their "consumer's eye" view of the service system, and their freedom from the legal and institutional constraints affecting many professionals. The authors indicate that advocacy is most effective when it involves collaboration between family members and professionals. Professionals can offer information about existing services, relationships with service providers, identification of important system issues, access to facts and figures, and understanding of how the system works.



The biggest impediment to the development of an organized advocacy force for parents of children with serious mental or emotional disorders has been the perspective that parents are the cause of their children's problems. Other barriers include difficulty arranging child care or respite care, crisis situations, family isolation or lack of confidence, transportation, work schedules, and financial constraints.

Recent advocacy developments are outlined including CASSP (Child and Adolescent Service System Program), a national program authorized in 1984 to improve services for children with serious emotional disorders and their families. Advice is given for how parents and professionals can work together as advocates. Professionals need to: work as partners with parents, listen carefully to parents and be open to new perspectives, be candid about barriers to change, be a resource to parents, invest in the development of parents as advocates, and insist on family participation. Parents need to: recognize that professionals also need support, acknowledge the constraints professionals face working within the system, be a resource to professionals, and foster an attitude of parent/professional collaboration within their organization.



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# **EMPOWERMENT**



Cochran, M. (1988). Parental empowerment in family matters: Lessons learned from a research program. In D.R. Powell (Ed.), Parent Education in Early Childhood Education (pp 23-52). Norwood, N.J.: Ablex.

The author's thesis is "the Family Matters Project has contributed substantially to the body of knowledge about how best to provide community support for family life."

The Family Matters Project was a two-year program from 1978-1980 with the goal of empowering parents. The program intervention involved the family's ecological system with an emphasis on reinforcing the family's strengths. The objective of the program was "to give positive recognition to the parenting role; encourage the exchange of information with and among parents about children, neighborhood, and community; reinforce and encourage parent-child activities; encourage mobilization of informal social support; and facilitate concerted action by program participants on behalf of their children." Two hundred and twenty-five urban families with a three-year-old child at the time of project enrollment participated for two years.

The author defends the importance and utility of the program against research citing "inadequacies in service delivery" and the enormous cost of the program. The author argues that the program has served as a catalyst to promote evolution of the environmental and parental empowerment focus in family support.

Cochran, M. (1987). Empowering families: An alternative to the deficit model. In K. Hurrelmann, F. Kaufmann, & F. Losel (Eds.), Social intervention: Potential and constraints (pp. 105-119). New York: Walter de Gruyter.

Problems affecting American families are described as primarily a function of society's embrace of the advantages of free enterprise capitalism without acceptance of responsibility for the "fall-out." It is ironic that the role of human services is "to move families toward independence, and away from public support or assistance" while, in practice, families are required to be totally dependent in order to become eligible for services. This philosophy has produced a "deficit model" of intervention that characterizes most American social programs. Professional literature and theory on the concept of empowerment is reviewed and a definition is developed.

The Family Matters program, presented as an alternative to a "deficit model" of intervention, relies on five assumptions: (1) all families have some strengths; (2) parents know more about their child than anyone from outside the family; (3) all varieties of family forms are legitimate; (4) fathers can contribute through an active role with the child and in household tasks; and (5) cultural differences are both valid and valuable. The program involved 276 families in Syracuse, New York and consisted of two basic components, home-visits and cluster-building. The home-visiting component utilized a shared parent knowledge base to give recognition to the parenting role and to reinforce and enrich parent-child activities. The cluster-building groups were a way for neighboring families to get to know each other and to get a sense from the group of what changes families perceived would contribute to improved living conditions in the neighborhood.

The workers developed a sense that empowerment is a process rather than an end state with three general steps of change: (1) perception of self; (2) relations with others; and (3) social



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action on behalf of the child. Data from the program evaluation showed that changes occurred in participant's perceptions of themselves, in relations with support networks, in communication with schools, and in the children's school performance.

Cooper C.S., Helms, G., Weeldrever, J. & Dunst, C.J. (1985, October). Interagency collaboration and parent empowerment. Paper presented at the Council for Exceptional Children/Division for Early Childhood, National Early Childhood Conference on Children with Special Needs, Denver, Colorado.

The authors describe a collaborative effort between Blue Ridge Community Action Head Start and the Family, Infant and Preschool Program (FIPP) in North Carolina. This interagency project was designed to accomplish the goals of improving services to children with disabilities and their families, improving the quality of parent involvement, and increasing mainstreaming activities for children with disabilities. The agreement between the two agencies was that FIPP would provide training for parent volunteers while Head Start would permit children with moderate to severe disabilities to enroll in the school program. The primary method of achieving these goals was through Project PAVE (Parents are Volunteers Who Excel), which provided training to parent volunteers in order to work as support staff in Head Start classrooms. Thirty-six parents and professionals were trained through this program, which provided workshops on topics such as behavior management, school readiness, motor development, play, and accessing community resources. Communication was emphasized as the key to building successful parent/professional partnerships.

Dunst, C.J. & Paget, K.D. (1991). Parent-professional partnerships and family empowerment. In M.J. Fine (Ed.), Collaboration with parents of exceptional children (pp. 25-44). Brandon, VT: Clinical Psychology Publishing Company.

The authors begin this chapter by addressing a dilemma in professionals viewing clients as capable. Many professionals feel that in viewing clients as capable consultants, their role of "expert" is threatened. The terms "partnership" and "collaboration" are then defined and compared with the aid of legal and business definitions. An operational definition of parent-professional partnerships is presented with minimal requirements that include: pooling of resources and expertise; agreement to enter into a collaborative arrangement; the qualities of loyalty, trust, and honesty; full disclosure of all "material facts"; and clear establishment of the powers of the partners and the locus of decision-making. The professional assists the family to evaluate options so the parents can make an informed decision.

The authors examine the terms enablement and empowerment and present a model of helping for professionals with three clusters of variables: (1) pre-helping attitudes and beliefs; (2) help-giving behavior; and (3) post-helping responses and consequences. Some of the pre-helping attitudes and beliefs that increase effectiveness of help-giving are: a positive stance toward help seekers; a strengths approach; a proactive posture in approach to helping relationships; and use of a promotion of competence model. Some of the help giving

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behaviors suggested are: active and reflective listening skills; assistance that matches the problem or need as defined by the help seeker; normative and non-demeaning aid and assistance; and allowing final decision-making to rest with the help seeker. Post-helping responses that are recommended include: accepting and supporting decisions made by help seekers; minimizing any sense of indebtedness; minimizing the psychological costs of accepting help; and maintaining confidentiality.

Dunst, C.J. & Trivette, C. M. (1987). Enabling and empowering families: Conceptual and intervention issues. School Psychology Review, 16(4), 443-456.

The authors provide an examination of what it means to be empowered, how different helping models (moral, medical, enlightenment, and compensatory) either promote or inhibit a sense of empowerment, and how professionals might intervene in ways that promote the acquisition of self-sustaining and adaptive behaviors that reflect a sense of empowerment. In addition, the authors suggest twelve principles to increase the likelihood that a person will become empowered as a part of help seeking. Some examples would be: locus of decision-making resting with the family, offering aid and assistance which is normative in terms of the client's culture, offering aid and assistance which is congruent with the client's appraisal of his/her problem or need, and conveying a sense of cooperation and joint responsibility for meeting needs and solving problems.

Dunst, C.J. & Trivette, C.M. (1988). An enablement and empowerment perspective of case management. Topics in Early Childhood Special Education, 8(4), 87-102.

The article explains the history of case management and defines several different models in order to present the enablement approach to case management as the superior approach in working with families.

The model is based on upon a definition of effective helping that describes (a) the types of help giver characteristics that are likely to create opportunities for families to become competent, (b) case manager functions that promote acquisition of competencies necessary for families to become actively involved in (c) identifying their needs and mobilizing resources, and (d) family empowerment as the major outcome of case management practices. The model emphasizes using parent-professional collaboration as the foundation for creating opportunities for families to become more capable and competent.

The authors note that the enablement model is directly in support of the goals and objectives of Public Law 99-457 and the Individualized Family Service Plan.

Hasenfeld, Y. (1987). Power in social work practice. Social Service Review, 61(3), 470-483.

Empowerment

The author examines the central role of power in social work practice. While many social work theories suggest a reciprocal relationship between client and worker based upon mutuality of interests and the contractual relationship, in fact the worker typically exercises considerable control over the client. A power-dependence perspective is used to analyze the worker-client relationship. The sources of power available to both client and worker are considered, with emphasis given to the worker's primary source of power--e resources and services controlled by the agency. When social work practice is considered from the power-dependence perspective that views practice as an exchange of resources between clients and workers, it is realized that practice effectiveness is enhanced by reducing the power imbalance between clients and workers. This is accomplished through empowering clients, thereby allowing them to make choices and gain control over their environment. Practice that aims to empower requires a shift in orientation from person to environment-centered practice, viewing problems not as the result of client deficiency but rather as the result of transactions between people and their environments and viewing the individual as a rich source of resources. Finally, strategies for enhancing client empowerment at three levels (case, organizational, and policy) are offered.

Pinderhughes, E.B. (1983). Empowerment for our clients and for ourselves. Social Casework, 64(6), 331-338.

The author explores the ways in which the dynamics of power influence human systems on multiple levels: intrapsychic, familial, community-ethnic-cultural, and societal. Murray Bowen's concept of social projection process is utilized to describe how victims (mental patients, criminals, alcoholics, minorities, and the poor) serve as system balancers and tension relievers in the social system. According to Bowen, societal projection occurs when the benefactors in a society maintain the victims in powerless positions by treating them as inferior; through this process, the system is balanced by having the powerless victims serve as recipients for the tension and conflict that exists in the system.

Family values may promote a sense of power at the expense of increasing vulnerability to conflict and dysfunction. Cultural values of African-American families are examined in regard to this problem. The influence of a sense of powerlessness on the boundary flexibility of families and the differentiation of family members is discussed.

The author advocates conceptualizing the treatment goal for all clients as empowerment. Emphasis is placed on influencing the external social system to be less destructive with enhancement of social supports stressed. Empowerment in treatment relationship involves a readiness to share power with clients. There is need for social workers to develop knowledge and skills about power dynamics in order to teach them to clients. Developing personal awareness of one's role as a benefactor in the societal projection process is crucial.



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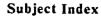
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# ANNOTATED BIBLIOGRAPHY: COLLABORATION BETWEEN PROFESSIONALS AND FAMILIES OF CHILDREN WITH SERIOUS EMOTIONAL DISORDERS

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