

**WORKING TOGETHER FOR CHILDREN:**  
**AN ANNOTATED BIBLIOGRAPHY ABOUT FAMILY  
MEMBER PARTICIPATION IN CHILDREN'S  
MENTAL HEALTH POLICY-MAKING GROUPS**

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## INTRODUCTION

### Scope and Overview of Bibliography

The recent movement in children's mental health toward greater family involvement in service planning, delivery and evaluation has complemented an earlier trend toward citizen involvement in policy- and decision-making. This annotated bibliography reviews literature that combines concepts from both movements: its focus is on the participation of parents and other family members who care for children with serious emotional disabilities in children's mental health policy-making groups, advisory boards, and other decision-making bodies. It is the authors' intent that several audiences will find this publication useful.

Family members of children with emotional, behavioral, or mental disorders who are currently involved in or contemplating serving on policy- or decision-making boards will find sources of practical information here. Individuals working as trainers or researchers will find sources of both usable ideas for enhancing family member participation and conceptual models and paradigms regarding increase participation.

Developed as part of the Families in Action Project of the Research and Training Center on Family Support and Children's Mental Health, this bibliography was distilled from a literature search that spanned articles, studies, and books from the 1960s to the present. Very little has been written with the specific focus of family member participation on boards related to children's mental health services. A wealth of literature on citizen participation in general emerged from the 1960s and 1970s (cf. Arnstein, 1971; Richardson, 1979; Cibulka, 1981; Blostein, 1985) the 1980s saw documentation of the move toward what has been termed "family-centered care" or "family-centered services" (cf. Friesen, Griesbach, Jacobs, Katz-Leavy & Olson, 1988; Dunst & Trivette, 1987) and throughout recent decades the theme of empowerment (cf. Kieffer, 1984; Zimmerman & Rappaport, 1988; Staples, 1990) has become a focus for study and writing. Along with pertinent literature focussed on advocacy (cf. Bersani, 1985; Apolloni, 1985; Mlawer, 1993) and minority family member involvement (Chavkin & Garza-Lubek, 1990; DeWind, 1982; Hauser, Johnson & Sevick, 1982; Lynch & Stein, 1987), these sources of information have been synthesized to create this modest bibliography.

### Description of Categories

The bibliography has been somewhat arbitrarily divided into three sections. First is a compilation of articles encompassing the conceptual approaches and constructs that underlie family member participation. This section, entitled **Theory: Approaches and Models for Understanding Family Participation**, includes literature reflective of historical trends in consumer and family member involvement on boards and committees.

This trend gained momentum with the passage of health care legislation in the mid-1970s that mandated "representative" consumer participation on governing bodies of neighborhood health and mental health care centers (see Metsch & Veney, 1976 and Cibulka, 1981, for two examples of discussion of these historical developments). Theories and models of empowerment are included in this section, as are models and rationale for citizen/consumer participation in general. A few relevant examples of writings about advocacy on behalf of adults with mental disabilities can be found here, along with contributions from Great Britain, Canada, and Australia.

The second section, labeled **Research: Investigating Participation**, includes both quantitative and qualitative studies on family-member participation in policy- or decision-making about children's educational, social, and mental health services. The relatively small size (twelve entries) of this section is reflective of the lack of research specific to this bibliography's focus. The majority of articles found in this category are from the fields of: (a) education (Chavkin & Garza-Lubek, 1990; DeWind, 1982); (b) special education (Lynch & Stein, 1987; McCullagh, 1988); (c) early intervention (Bailey, Buysse, Smith & Elam, 1992; Saylor, Elksnin, Farah & Smith, 1990); and (d) health care (Cibulka, 1981; Hausner, et. al. 1982). Just two articles (Tarico, Low, Trupin & Forsyth-Stevens, 1989; Vosler-Hunter & Hanson, 1992) have a specific focus on family member involvement in decision-making about children's mental health services. Four articles incorporate explicit consideration of ethnicity and multicultural issues in the research undertaken. They include: (a) Chavkin & Garza-Lubek (1990); (b) DeWind (1982); (c) Hausner, et. al. 1982; (d) Lynch & Stein (1987). An emergent issue in the field of social scientific research is that of consumer involvement in formulating and carrying out research. The article by Sohng (1992) is especially relevant to this issue. Other generic questions of research methodology and design in this area of inquiry are addressed by several of the entries in this section.

**Practice: Strategies and Experiences Regarding Participation** is the final category of this bibliography. Practical strategies and tactics for enhancing effective involvement of family members on boards are represented here, along with examples of programs around the nation that have attempted to increase family member participation in various forms. The manual by Hunter (1994), produced as part of the work of the Families in Action Project, is an especially comprehensive attempt at pulling together practical, effective strategies for family member participants. This section is relatively brief and heterogenous. Some writers address strategies for advocacy in general (Apolloni, 1985; Issues and Advocacy Committee of Parent to Parent of Florida, Inc., 1989); others focus on advocacy at the state legislative or policy level (Cromwell, Howe & O'Rear, 1988; Rissmeyer, 1988; Trupin, McDermott & Forsyth-Stephens, 1989; VanDenBerg & Donner, 1986). Several describe specific models for gathering family member input, like the "Concerns Report Method" outlined by Fawcett, Seekins, Whang, Muiu and Duarez deBaleazar (1982) or the process utilized by the Kansas Family Input Program (VanDenBerg & Donner, 1986). For readers who enjoy humor along with serious discussion two entries are commended to: Gartner (1988) and the document *Advocacy*

*through Parent Power Via Understanding the Legislative Process and Networking* (Issues and Advocacy Committee of Parent to Parent of Florida, Inc., 1989). Both communicate practical concepts through humorous language. Finally, experiences of family members who have participated in policy- and decision-making bodies are documented eloquently by Mayer (1994).

## **Indexes and Reference List**

For enhanced utility of this bibliography itself, both author and subject indexes have been compiled. The subject index includes references to the "level of change" (e.g., advisory boards, personal strategies, legislative change, community change, service system reform, or constituency building) featured in each article. Subject headings include both phrases and topics related to the bibliography's content. This subject index, in turn, is related to the list of **Key Words** that follows the citation for each article, which can serve as a quick guide to the focus of a given entry. A complete reference list, comprised of citations for all entries and additional references from the text of this bibliography, is the final section of the publication.

## **Overview of the Families in Action Project**

The Families in Action Project was in its final phase as this bibliography went to press. The goals of this five-year project were to develop and evaluate strategies that speak to the skills and knowledge needed for effective participation by family members on boards, and to establish committees and other bodies whose mandates include services to children with emotional disorders and their families. Initially, activities of the project included gathering of information about family member participation through telephone interviews, structured group and individual interviews, and site visits by project staff. Later work involved interventions -- primarily involving training activities -- and the development, dissemination and analysis of evaluative questionnaires, and "key informant" interviews with project participants located in five sites nationwide. The sites included parent groups in Maryland, Rhode Island, Oregon, and upstate and western New York. A monograph describing the project's history, research and training processes, and evaluation findings is available from the Research and Training Center on Family Support and Children's Mental Health (a Research and Training Center publications list and order form is included after the indexes and reference list).

## **Acknowledgments**

The authors, staff of the Families in Action Project, would like to first and foremost acknowledge the efforts, experiences, and energy of the family members whose active participation in both committee work and in the research and training elements of this

project is the inspiration for this bibliography. We wish to extend our appreciation to Judy Mayer, who undertook an initial review of the literature that greatly informed this final version, and whose personal activism on behalf of her children exemplifies the spirit of the family member participation that this bibliography is about.

## THEORY: APPROACHES AND MODELS FOR UNDERSTANDING PARTICIPATION

**Allen, D.A., & Hudd, S.S. (1987).** Are we professionalizing parents? Weighing the benefits and pitfalls. *Mental Retardation*, 25(3), 133-139.

**Key Words:** special education, advocacy, parent involvement, parent roles, advisory boards, benefits and costs of participation, professional practice

**Synopsis:** This article reviews research pertaining to parent involvement in programs for children with handicaps. The authors discuss traditional and current roles for parents in decision-making, advocacy, case management, structured teaching, and program evaluation, reviewing the pros and cons of increasing parent involvement in each area. The pitfalls of parent "professionalization" are highlighted, as is the need for individualization of the nature and degree of parents' involvement. In conclusion, the authors assert that increased parent involvement must occur as a result of the parent's initiative, and not simply to lessen professional responsibilities. [Authors' abstract, edited.]

**Comments:** The article's explicit focus is on professionals working in the field of special education, however, the sections discussing parents' roles as advocates and program evaluators are particularly applicable to parent-professional collaboration on boards and committees. The authors stress careful consideration of parent participants' needs, time, and energy, a point of view developed further by Mlawer (1993, abstracted below).

**Arnstein, S. (1971).** Eight rungs on the ladder of citizen participation. In E.S. Cahn & B.A. Passert, (Eds.), *Citizen Participation: Effecting Community Change* (pp. 69-91). New York: Praeger.

**Key Words:** models of participation, citizen power, community change

**Synopsis:** In this classic exposition of the range -- and limitations to that range -- of citizen participation, the author develops a conceptual framework of an eight-rung ladder of increasing power. The model includes the following "rungs": (1) manipulation and (2) therapy, both of which are viewed as non-participation; (3) informing; (4) consultation and (5) placation, all of which are described as degrees of tokenism; (6) partnership; (7) delegated power; and (8) citizen control, which are all seen as degrees of citizen power. Explanations and examples of each are given, with the

prevalence of non-participatory and tokenistic participation emphasized. The status quo's potential for diluting citizen power or rendering it ineffective is stressed throughout, *no* explicit strategies for change are proposed, beyond mobilizing protests or taking legal action.

**Comments:** The ladder of citizen participation provides a useful model for critical examination of the actual degree of power which parents and family members might have on a given committee or board. As Arnstein notes, the model "is designed to be provocative" and its emphasis on the political aspects of participation is well-placed.

**Belin, A. (1981). Reaction of a frustrated citizen. *Community Mental Health Journal*, 17, 83-91.**

**Key Words:** adult mental health, training for participation, citizen-professional partnership, professional attitudes, power dynamics on boards, advisory boards

**Synopsis:** The author discusses the need for building a partnership between mental health agency staff and the governing citizen board. Written from the viewpoint of an experienced citizen board member, the article raises three key issues: (1) the issue of citizen-participants being seen as unequal to staff in power and expertise; (2) the ongoing struggle for power inherent in board-staff relationships; and (3) the need for boards to involve non-agency staff, professionals and citizens. The need for relevant training for citizen-participants is discussed, along with the concept of training for staff as well. Staff training should aim, in part, to give staff a better understanding of the limits to their power, while citizen board training should enable citizens to understand their right to share power. The author notes that boards need commitment from professionals to provide appropriate assistance.

**Comments:** The first two issues Belin discusses can arise in advisory and policy-making boards as well, and awareness of them can help prepare family member participants to confront unequal treatment. Belin's description of the difficult choices that frequently confront boards, and of the often slow pace of institutional change, is also instructional.

**Bersani, H. (1985). Advocacy: The role for parents' groups. *Exceptional Parent*, 15(3), 28-30.**

**Key Words:** advocacy, parent groups, constituency building, personal strategies

**Synopsis:** The relatively recent shift of many parent groups' focus from monitoring services to actual service provision is noted and decried. The author calls for a shift of the role of parent groups back to advocacy, arguing that advocacy is sorely needed and cannot be performed effectively when a group is caught up in administrative tasks. Service provision should be left to public agencies, the author maintains, since they have been legislatively mandated to provide services. Parent groups can be effective in changing public attitudes, monitoring service quality, influencing local, state and national legislation, and in following through on needed litigation.

**Comments:** The author's arguments about the pressing need for parental involvement in advocacy and monitoring, and the clear appropriateness of such active involvement, support the general philosophy of family member participation on boards. The value of an activist approach for family members is underscored throughout the article.

**Biegel, D. & Naparstek, A. (1979). Organizing for mental health: An empowerment model. *Journal of Alternative Human Services*, 5(3), 8-14.**

**Key Words:** empowerment, citizen-professional partnership, mental health policy, community change

**Synopsis:** The authors present a "community mental health empowerment model," utilizing strengths and resources of neighborhoods as the source of community empowerment. The authors emphasize the need for integration of lay helpers with mental health professionals. This model of empowerment is based on a systems approach. It aims to effect change in the interrelated administrative, fiscal, and legal barriers to effective functioning of mental health services. The authors argue that the answer to current mental health and human service problems is not new programs, but a new policy framework that enhances neighborhood support systems. Although the need for state policy initiatives is stated, specific means of accomplishing this goal are not offered.

**Comments:** The discussion of integrating "lay helpers" (including family members) has direct relevance to issues around family member participation on

boards. The article's discussion of the strengths of a neighborhood support systems approach makes several points that parallel advantages of involving family members in the system of care, including: (1) building on the strengths of a community (family); (2) building on the ability of community residents (family members) to know what will work in their community; and (3) reinforcing lay helper (family member) competency while demystifying the role of professionals. The authors' advocacy of a new policy framework can provide ideas for family members acting as advocates as well.

**Blostein, S. (1985). On citizen boards: Training is not the answer. *Administration in Mental Health, 13*(1), 69-79.**

**Key Words:** training for participation, community mental health centers, roles of participants, advisory boards

**Synopsis:** Community involvement through the use of citizen review boards has long been a cornerstone of the ideology of community mental health centers. When boards have been perceived as ineffective or functioning poorly, training of board members has frequently been the proposed remedy. Three categories of board training are outlined, and their failures to resolve poor board functioning are asserted. The author argues that boards are doomed to fail because of inherently conflictual roles and responsibilities, and that modifying demands and expectations of boards should take precedence over more training. A model drawn from the private, for-profit sector is described and advocated for, where board members represent and strive to maintain the corporate interests of the agency rather than attempting to act as community representatives. Three key roles are described in this new model: (1) policy formulation; (2) consultation with top management; and (3) performance evaluation of the director.

**Comments:** The author's critique of citizen review boards could be applied to other decision- and policy-making boards in order to gain insight into problems of ineffectiveness or role conflict. A thoughtful counterpoint to the view that training can solve problems of board ineffectiveness, this article is highly relevant to persons in charge of planning training for or staffing boards or policy-making groups. The model of reconceptualizing boards' missions and roles proposed in the article, while thought-provoking, may have limited utility for family members involved with boards that affect their children with serious emotional disorders.

**Chamberlin, J., Rogers, J.A. & Sneed, C.S. (1989). Consumers, families and community support systems. *Psychosocial Rehabilitation Journal*, 12(3), 93-106.**

**Key Words:** adult mental health, family involvement, community support system, advisory boards, community change, legislative change, constituency building

**Synopsis:** The community support system (CSS) concept is based upon the principles of consumer involvement and empowerment. In recent years, adult consumers and families have become powerful forces for change in the mental health system and have advocated for the development of CSSs. This article traces the growth of the consumer movement, discusses the role of self-help in CSSs, and presents the perspective of families regarding the CSS concept. [Journal abstract.]

**Comments:** Parallels in the process and value of consumer participation in decision- and policy-making for both adult and children's mental health can be drawn throughout. The article makes specific mention of consumer involvement on advisory boards, and notes a specific resource, a pamphlet produced by the National Mental Health Consumer Self-Help Clearinghouse. It is titled, "Making Our Voices Heard: Consumer Representation on Decision-Making Committees."

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

**Key Words:** developmental model of participation, activist role for family members, personal strategies, advocacy, professional attitudes, service system failures

**Synopsis:** This article explores the development of activism among parents of children with disabilities. Based on research with parents from a symbolic interactionist perspective, it discusses the predisposing conditions and situational contingencies [see Comments, next page] that move parents to become activists for their children. The author views parental activism as a response to the failure of society to provide sufficient or appropriate resources to meet the needs of disabled children and their families. This activism involves seeking information, asserting control, and challenging authority. Development of such an activist/advocate role is nurtured by interactions with others in similar situations and may result in a careerlike pattern, or entrepreneurship, as a way of life. [Journal abstract, edited.]

**Comments:** The “predisposing conditions and situational contingencies” mentioned above are divided into pre- and post-natal time periods. Before the birth of a child with a disability, family members typically lack experience with disabilities, initially defer to professional authority, and expect to maintain a “normal” lifestyle while being “good parents.” After the child's birth, family members often experience a sense of confusion, uncertainty, and even meaninglessness, coupled with the experience of powerlessness in the face of professional dominance. Normal emotional bonding with their child; the experience of the lack of societal resources to adequately care for the needs of children with disabilities; interactions with extended family, friends, and old and new “significant others;” exposure to information from the media; significant experiences; and formal training can all move family members toward the role of activist that the author explores. The “career paths of parents of disabled children” model developed by Darling in this article may be helpful to both family members and professionals in understanding options and choices facing families of children with severe emotional disorders. These options include: (1) adaptive responses of retreatism, a withdrawal into isolation; (2) crusadership, the “entrepreneurship” that Darling focuses this article on; or (3) normalization, when the child and family's needs are either relatively well met or have become an accepted, routine part of life. Families involved in policy- and decision-making bodies are likely to describe themselves as being in one of the last two “paths.”

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

**Key Words:** empowerment, professional interventions, professional attitudes, personal strategies, family member-professional collaboration

**Synopsis:** This paper proposes to examine the meaning of empowerment, how different helping models either promote or inhibit a sense of empowerment, and how professionals might intervene with families in ways that encourage the acquisition of self-sustaining and adaptive behaviors that reflect such empowerment. The authors describe an “enabling model of helping” and delineate a set of intervention principles that professionals can use to increase the likelihood of children and families becoming empowered as part of help seeking and help giving exchanges.

**Comments:** The authors also present information useful in undertaking case advocacy. Useful for the theoretical model it presents, the article can also support family members in their interactions with professionals.

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

**Key Words:** collaboration, family-centered care, developmental model of families, Child and Adolescent Service System (CASSP), constituency building, personal strategies, community change, policy change, service system reform

**Synopsis:** This article describes the history of family member-professional collaboration toward translating the goals of “family support” into policies, programs, and services in the larger system of care for children and youth who are severely emotionally disturbed. Beginning with a short history of family member involvement in caring for children with emotional, mental, and physical disorders, the authors describe the shift away from institutional care to a home-based, “family-centered care” approach. Types of family support services are mentioned. A developmental model of families' movement through stages of crisis, need for information and education, readiness for skills development, and, for some, involvement in service development and/or advocacy is outlined as well. The article gives examples of regional and national level activities where family members and professionals have worked together, and closes with a description of a parent organizing project in Wisconsin.

**Comments:** Written by pioneers in the field of “family-centered care,” this article offers useful historical background and organizing strategies for family members and professionals interested in policy-making.

**Imershein, A.W. & Miller, E.T. (1980).** **The impact of consumerism on health care change: Alternatives for the future? *Journal of Sociology and Social Welfare, 7*(3), 464-476.**

**Key Words:** health care, consumer participation, empowerment, constituency building, advocacy, barriers to participation, advisory boards

**Synopsis:** The limited impact that consumer representatives have had in the decision-making realm in health care is analyzed. Four categories of explanatory factors are described: (1) the lack of preparation of consumers for new roles as decision-makers; (2) the established power of professionals, who have a vested interest in maintaining control across organizational settings that affect their daily practice; (3) the existence of system characteristics that discourage development of consumer strength; and (4) the use of consumers as legitimators of advisory and management board decision-making with negligible change in the types of decisions or attitudes of the decision-makers themselves. The authors move on to a discussion of structural barriers to change, including the lack of an institutional, structural base for consumers that could add power to their perspective. The differing perspectives and possibilities for changing the system offered by two broad groups of consumer advocates are discussed as well. The authors characterize the first group as highly vocal advocates for fundamental systemic change; the second group is oriented toward individual responsibility for self-care, with the aim of minimizing the need for health care through prevention.

**Comments:** The authors' analysis of the problems experienced in consumer participation is especially relevant to potential problems faced by family member participants on boards and committees. Their discussion is complemented well by Metsch & Veney's (1976, an article described below) proposed strategies for increasing the effectiveness of consumer participation.

**Kieffer, C.H. (1984). Citizen empowerment: A developmental perspective. In J. Rappaport & R. Hess (Eds.), *Studies in empowerment: Steps toward understanding and action* (pp. 9-36). New York: Haworth Press.**

**Key Words:** empowerment, developmental model of participation, family member-professional collaboration, community change, personal strategies

**Synopsis:** Since the late 1970s, the notion of empowerment has appeared with increasing frequency in discussions of preventive social and community intervention. While the idea of empowerment is intuitively appealing both for theory and practice, its applicability has been limited by continuing conceptual ambiguity. Based on a small sample size study of emerging citizen leaders in grassroots organizations, this article proposes a view of empowerment as a necessarily long-term process of adult learning and development. In this framework, empowerment is further described as the continuing construction of a multi-dimensional

participatory competence. This conception encompasses both cognitive and behavioral change. Implications for practice are also addressed. [Journal abstract.]

**Comments:** The developmental model theorized by Kieffer incorporates four phases, or “eras,” as the author labels them. The movement from powerlessness to the final stage, “the era of commitment,” when citizens/parents have developed a fully realized participatory competence, is accomplished only through practice and reflective critical awareness. Implications for parents involved in boards include the need for including structure and time for critical and constructive examination of experiences with the system or situation they are trying to affect. Also, the value of collaboration with an external parent or professional acting as a mentor is raised, as is the pulling together of accurate and extensive knowledge about the system targeted for change. A final implication of this developmental model is the need to recognize and respond to the changing conflicts that parents experience as they move along the continuum of empowerment.

**Lord, J. (1989). The potential of consumer participation: Sources of understanding. *Canada's Mental Health, 37*(2), 15-17.**

**Key Words:** consumer participation; empowerment; consumer-professional relationship; professional attitudes; constituency building; advisory boards.

**Synopsis:** The author begins by clarifying the meaning of “consumer participation,” including participation at individual service, agency/organization (including boards and committees), and community to national policy-making levels. Three “sources of understanding” of the potential of consumer participation are discussed: (1) listening to consumers and their perspectives; (2) gaining insight from partnership models for change; and (3) learning from consumer-directed organizations. Suggestions for structuring adult consumer participation to maximize empowerment and equality are included. These suggestions include professional practices of careful listening to consumers' perspectives and consumer inclusion in needs assessment.

**Comments:** Lord's identification of three sources of understanding of the potential for adult consumer participation is useful to both family member-advocates and family-centered professionals. The discussion of partnerships includes several points that are directly relevant to the experience of

family members serving on boards, including the need to build trust, the need for strong leadership and collaborative planning, the desirability of professionals undergoing “somewhat of a role change,” and the need to involve more than just token numbers of consumers.

**MacNair, R.H. (1981). Citizen participation as a balanced exchange: An analysis and strategy. *Journal of the Community Development Society, 12*(1), 1-9.**

**Key Words:** models of citizen participation, advisory boards, power dynamics on boards, training for participation

**Synopsis:** Using exchange theory to identify aspects of a “balanced exchange,” the author goes on to describe five types of citizen participation: (1) a balanced partnership; (2) domination of the exchange by the agency; (3) domination of the exchange by citizens; (4) no exchange (“rubber stamping” of agency plans); and (5) another category of no exchange, this time featuring forced control by citizen groups. Five key dimensions of the exchange process are listed, including clarity of expectations, saliency of problems, controversy, power, and external constraints.

**Comments:** The concepts developed in this article may provide useful content for training participants in boards. Understanding where a given board is functioning among the categories can lead to appropriate strategies for change.

**Metsch, J.M., & Veney, J.E. (1976). Consumer participation and social accountability. *Medical Care, 14*, 283-291.**

**Key Words:** health care consumers' participation, training for participation, evaluation of participation, community change, professional attitudes, family member-professional collaboration

**Synopsis:** Concepts of consumer participation are discussed, including description of professionals as participants, consumer representatives, and consumer-professional interaction. The authors emphasize that training will increase consumer confidence in the legitimacy of their participatory role, increase substantive knowledge, and improve planning skills. Training also helps consumers redefine their role and move on to higher levels of activity. Consumers benefit from training programs involving sustained effort and shared planning. Professionals also often need

training in order to share decision-making responsibilities with consumers. The authors mention several proposed criteria for measuring outcomes of consumer participation: they also state that guidelines for implementing consumer participation cannot be generic, but must be program specific and reflect program goals, settings and complexity. Further, consumers need clear roles regarding participation, and the specific needs of each consumer group should dictate planning for training. Finally, Easton's (1965) equilibrium model on how the political system responds to stress is related to consumer participation.

**Comments:** This article provides a good overview of the complex and often controversial issues involved in consumer participation. The authors point out the importance of considering professional attitudes toward consumer participation; the effectiveness of consumer participation can be undermined by professionals determined to “defend their turf.” The impact of consumer participation can be further limited, the authors contend, by vague eligibility requirements and inappropriate processes used in selecting consumer representatives. In their discussion of consumer-professional interaction, the need for early, ongoing and consistent community involvement is asserted, along with the empowering -- or possibly neutralizing, depending on the content -- effect of training for participation. The need for careful planning, including individualized training, if necessary, for parent participation on boards is an implication that follows the authors' analysis. The article's focus is on consumer participation in health care program decision-making; however, the issues identified and strategies proposed here are applicable to family member participation in other systems.

**Mlawer, M.A. (1993). Who should fight? Parents and the advocacy expectation. *Journal of Disability Policy Studies*, 4(1), 105-116.**

**Key Words:** advocacy, benefits and costs of participation, professional practice, constituency building, personal strategies, advisory boards

**Synopsis:** This article offers a strident critique of current policies and practices that the author believes combine to create an “advocacy expectation” that “good parents” should invariably become better educational advocates for their children with disabilities. The potentially harmful effects of this expectation are discussed; it is contrasted with the philosophy of normalization of parents'/families' experience; and recommended changes in professional roles, funding priorities, and program development are outlined.

**Comments:** A potential antidote to overzealous enthusiasm, this article can serve to sensitize both professionals and parents to the costs, as well as the benefits, of participation in advocacy and policy-making.

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

**Key Words:** developmental disabilities, family member participation, barriers to participation, community change, legislative change, personal strategies

**Synopsis:** The important role of family involvement in services to people with developmental disabilities is recognized. A conceptualization of family involvement, derived from a qualitative study of involvement from the perspective of family members themselves, is presented. The authors identify a framework of family involvement, incorporating four system levels (individual, program/agency, community, and society) and five role opportunities for family members (treatment agent, planner, advocate, evaluator, and consultant/educator). Barriers to involvement are described. The authors outline a three-phase process for promoting family involvement, comprised of contracting for involvement, developing a support system for involvement, and monitoring and evaluating involvement. [Journal abstract, edited].

**Comments:** This article offers a useful set of concepts for understanding family member participation. The authors' discussion of barriers to participation identifies three categories of obstacles, each of which is relevant to family member participation on boards and advisory committees: (1) resource barriers, including the time, opportunity and material supports needed to make involvement possible; (2) training and skill barriers, which involve specific knowledge and skills required for successful participation; and (3) communication barriers, related to professional-family member interaction and mutual understanding. The process of "promoting family involvement" stresses careful consideration and regular monitoring of family preferences, needs, and capacities, in order to renegotiate participation when appropriate and lessen the role strain that families of children with disabilities (whether developmental, behavioral, or emotional) can experience.

**Nash, J.K. (1990). Public Law 99-457: Facilitating family participation on the multidisciplinary team. *Journal of Early Intervention, 14*, 318-326.**

**Key Words:** early intervention, Individualized Education Plan (IEP), Public Law 99-457, family member participation, strategies for effective participation, personal strategies, advisory boards

**Synopsis:** The requirements for family participation on multidisciplinary teams under PL 99-457 are presented, followed by a brief review of the literature on family participation on existing multidisciplinary teams. The identification of factors that influence team functioning is informed by a review of the literature on teamwork. The implications of these factors for family participation on the multidisciplinary team are discussed, and strategies for facilitating family participation are outlined. [Journal abstract, edited.]

**Comments:** Although written with Individualized Education Plan teams in mind, the key concepts from this article can be easily applied to family participation on boards with wider mandates and purposes.

**O'Donnell, S. (1993). Involving clients in welfare policy-making. *Social Work, 38*, 629-635.**

**Key Words:** welfare clients' participation, benefits and costs of participation, advisory boards, personal strategies

**Synopsis:** An Illinois-based effort to involve welfare recipients and community groups in developing and implementing statewide welfare-to-work policy is the focus of this article. Unique contributions of the aforementioned groups in shaping policy are discussed, along with the benefits of including clients and advocacy groups in the policy-making process. Consideration is given to dilemmas raised for social workers and other policy professionals by participatory policy-making.

**Comments:** The author's discussion of consumers' key contributions to policy-making constitutes a strong case for consumer participation, generalizable across fields.

**Ovretveit, J. & Davies, K. (1988). Client participation in mental handicap services. *Health Services Management, 84(5)*, 112-116.**

**Key Words:** models of participation, adult mental health, professional attitudes, constituency building, community change

**Synopsis:** The author describes the participation structure in the Rhondda District of Mid-Glamorgan, Wales, and addresses the main problems raised by clients. The authors state that when defining participation clarification is needed of two points: who the clients are, and what meanings and purposes are implied by participation and representation. Three different models, along with the implicit assumptions about the purpose of participation carried by each, are presented: (1) "consultation" mode; (2) the "client-directed" model; and (3) the "education/joint decision" model. The role of representation is interpreted in three different ways, including personal opinion, typical client, and representative (of a group of client-constituents). The need for a structure for participation is stated, along with the view that the process whereby participation is developed will influence the type of participation which will take place.

**Comments:** Review of the primary problems encountered by clients regarding participation offers corroboration and validation to the barriers to participation faced by family members in North America (Valentine & Capponi, 1989, included below, address this issue concisely). The value of clarifying family members' roles and of educating professional staff about these roles is also directly relevant to family involvement on boards.

**Paulson, R.I. (1991). Professional training for consumers and family members: One road to empowerment. *Psychosocial Rehabilitation Journal, 14(3)*, 69-80.**

**Key Words:** empowerment, family member-professional collaboration, personal strategies, constituency building

**Synopsis:** This article describes the experience of participants in an innovative Masters of Social Work specialized mental health training program. The program trained consumers and family members as mental health professionals to work with persons with major mental illness and their families. The author focuses on the issues and problems involved in successfully integrating consumers and family members into traditional academic programs and mental health settings. The unique contributions of consumers and family members as mental health professionals are

presented, along with the methods employed in securing the participation of family and consumer groups in the program planning, design, and implementation. [Journal abstract, edited.]

**Comments:** Issues generic to family member-professional collaboration are well-covered by this article. The value of developing programs that promote inclusion of consumers' (and family members') points of view is supported.

**Petr, C.G. (1991). A “consumer-friendly” model of implementation. *Administration in Social Work, 15*(3), 67-82.**

**Key Words:** policy implementation, legislative change, community change, advocacy, professional practice, training for participation, power dynamics on boards

**Synopsis:** Policy analysts and citizen groups have long struggled with the complexities of the policy implementation process. The model presented here empowers students, community organizers, and consumers with theoretically sound, practically useful procedures for assessing the extent to which social agencies are implementing a particular policy or piece of legislation. It also identifies key implementation variables for citizens to target in their agency change efforts. They are: (1) the participation of front-line staff in decision-making processes about the organization's objectives; (2) their agreement with the meaning of the objectives; (3) their experience and/or training related to carrying out the objectives; and (4) their level of job satisfaction. Specific research results are presented to illustrate the practical utility of the model. [Journal abstract, edited.]

**Comments:** The model Petr proposes may be helpful to family members participating on boards. It involves four stages: (1) defining a policy's goal in operational terms; (2) providing a tool for assessing the degree of implementation in both intent and practice; (3) understanding and influencing the organizational processes that account for the level of implementation identified; and (4) providing guidelines to help consumers identify a logical place to start. This model holds promise for use in training family member/citizen/consumer participants. Results of the study used in developing the model have become the foundation for a training program aimed at empowering families of children with emotional disorders.

**Richardson, A. (1979). Thinking about participation. *Policy and Politics*, 7, 227-244.**

**Key Words:** empowerment, models of participation, evaluation of participation, philosophical basis for participation, advisory boards

**Synopsis:** The author defines the meaning of participation as “an activity undertaken by one of more individuals previously excluded from the decision-making process in conjunction with one or more other individuals who were previously the sole activists in the process (p. 228).” The article's basic premise is that participation “schemes” (the author is from Great Britain) are essentially methods of achieving the interaction of two groups. A model of participation based on bargaining, with that term used in a broad sense to include any attempts by the parties involved to influence the thinking and activities of the others, is developed. This model includes two views of participation: (1) an exchange of information, when groups have identical aims; and (2) the use of schemes that provide a means of furthering the aims of one group at the expense of the other through the exercise of power, when there are opposing aims between the groups involved. The author develops the bargaining model from the latter view, stressing the importance of seeing bargaining as a process. Points to consider in the evaluation of participation are discussed as well.

**Comments:** In examining the assumptions underlying ideas about participation, the author critiques and expands on Arnstein's (1971) “ladder of participation” model. The bargaining model developed by Richardson (1979) is useful in understanding interactions among decision-makers, whether on tenant participation councils in Great Britain or other types of groups.

**Staples, L.H. (1990). Powerful ideas about empowerment. *Administration in Social Work*, 14(2), 29-42.**

**Key Words:** empowerment, community change, advisory boards, personal strategies, philosophical basis for participation

**Synopsis:** The author embarks on a theoretical exploration of the meaning of individual and collective empowerment and the relationship between the two. Emphasis is placed on the requirement for social action in order to bring about empowerment of powerless groups; individual empowerment, while desirable, cannot address structural inequality and

powerlessness. A critique of the predominantly individualistic focus of empowerment research is offered. The article concludes with a discussion of empowerment as both process and product.

**Comments:** Implications of Staples' analysis for family members participating on boards include recognition of the essential meaning of empowerment -- the ability to take effective action on behalf of self, whether that self is an individual or a collective one. The need to maintain a focus on collective empowerment in order to effect social change -- including change in an agency or program's policies affecting children with emotional disabilities -- is another implication for parent participants.

**Valentine, M.B. & Capponi, P. (1989). Mental health consumer participation on boards and committees: Barriers and strategies. *Canada's Mental Health, 37*(2), 8-12.**

**Key Words:** advisory boards, adult mental health participation, barriers to participation, strategies for effective participation, personal strategies, constituency building

**Synopsis:** The article provides an overview of factors related to the participation of consumers of mental health services on boards and committees. Six primary barriers to effective consumer participation are addressed: (1) incongruency between stated values and actual practice; (2) tokenism; (3) lack of representativeness; (4) role strain; (5) poor communication; and (6) economic factors. Strategies are proposed to increase the potential for effective implementation of consumer participation. The article concludes with a broad statement affirming interdependence and the potential for increasing the effectiveness of boards and committees and exerting a positive influence on the system. [Journal abstract.]

**Comments:** The barriers to participation identified by the authors are consistent with the experience of parents of emotionally disturbed children who are involved on boards and committees. The strategies to overcome these barriers proposed in the article are logical, practical, and deserving of consideration by parents and professionals alike.

**Zimmerman, M.A. (1990). Taking aim on empowerment research: On the distinction between individual and psychological empowerment. *American Journal of Community Psychology*, 18(1), 169-177.**

**Key Words:** empowerment, philosophical basis for participation, constituency building, advisory boards

**Synopsis:** In this article, the author makes a distinction between psychological empowerment and individually-oriented conceptions. Psychological empowerment includes person-environment fit and cultural and contextual issues; individually-oriented models are primarily lists of traits, and as such may be antithetical to the idea of empowerment. Suggestions for research strategies for continued work on empowerment are outlined. [Journal abstract, edited.]

**Comments:** The author's arguments can contribute to the philosophical base supporting consumer/family member participation. Zimmerman's distinction between individual and psychological empowerment is especially useful in raising a more holistic context for participation.

## RESEARCH: INVESTIGATING PARTICIPATION

**Bailey, D.B., Jr., Buysse, V., Smith, T. & Elam, J. (1992).** The effects and perceptions of family involvement in program decisions about family-centered practices. *Evaluation and Program Planning*, 15, 23-32.

**Key Words:** family-centered practice, professional attitudes, family member participation, early intervention, advisory boards, constituency building

**Synopsis:** This article describes the perceptions and effects of parent participation in a workshop designed to help professionals working in early intervention programs for young children with disabilities become more family-focused in their work. Results indicate that parent presence influenced professionals' perceptions of the need for change in program practices. Parents and professionals who experienced parent presence were positive about the experience, and professionals who attended the workshop without parents felt strongly that parents should have been there. [Journal abstract, edited.]

**Comments:** The results reported in this article strengthen arguments for including family members on policy-making bodies. The study design includes use of the Family Orientation of Community and Agency Services (FOCAS) scale (Bailey, 1990) to measure family member/professional perceptions of degree of inclusion of families in programs.

**Brown, C. & Ringma, C. (1989).** Consumer perspectives on disability services in Queensland: The long road to new directions. *Australia and New Zealand Journal of Developmental Disabilities*, 15(1), 41-48.

**Key Words:** adult mental health consumer participation, evaluation of service delivery, service system failures, research, personal strategies

**Synopsis:** This article is based on a consumer study (Brown & Ringma, 1988) of twenty-four dependents who were intellectually and physically disabled using a range of nongovernmental welfare organizations in South-East Queensland (Australia). Key points summarized by the article include: the perspectives of consumers and parents of dependent consumers on the accessibility of information about services, the exercise of consumer choice in service provision, inadequacies in the service delivery system, and consumer participation in decision-making regarding service delivery. Comparison is drawn between these consumer perspectives and

the goals of the Australian Disability Services Act of 1986, which called for opening avenues for consumer participation in the planning and operation of individual services, along with consumer input on major policy development and program changes.

**Comments:** Findings on consumer participation in agency policy-making include widespread non-consultation of consumers, their non-participation in decision-making, and their expression of personal reluctance, combined with self-perceived inadequacy, to take part in agency decision-making. These findings are similar to the issues discussed throughout the literature in the United States regarding “barriers to participation” on policy- and decision-making bodies.

**Chavkin, N.F. & Garza-Lubek, M. (1990). Multicultural approaches to parent involvement: Research and practice. *Social Work in Education, 13*(1), 22-33.**

**Key Words:** minority parent participation, education system change, research, constituency building, advisory boards, personal strategies

**Synopsis:** This two-part article makes a case for taking a multicultural perspective on parent involvement in education, using a research study and case example. Part one reports on an exploratory study that included responses from 1,188 African-American and Hispanic parents. Attitudes and practices of minority parents regarding involvement in their child's education are discussed, including their interest in participation in advocacy and decision-making bodies. The major finding of the study was that African-American and Hispanic parents are concerned about their children's education and wanted an active role in it. Part two describes a case example involving the use of effective multicultural practices, built upon effective cross-cultural communication, to ensure active participation of minority parents in their children's education. [Journal abstract, edited.]

**Comments:** While this article is directed at school social workers, both the study's findings and the lessons drawn from the case example are relevant to involving African-American and Hispanic parents in policy-making bodies.

**Cibulka, J. (1981). Citizen participation in the governance of community mental health centers. *Community Mental Health Journal*, 17(1), 19-36.**

**Key Words:** citizen participation, participation in policy-making, Community Mental Health Centers Act of 1975, P.L. 94-63; research, demographics of advisory board members, community change

**Synopsis:** The author reviews the theories undergirding citizen participation in governance and presents several models of governance. A mail survey of 220 community mental health centers revealed that most centers did not meet the participant requirements of Public Law 94-63, the Community Mental Health Centers Act, as amended in 1975. Requirements for broad representation of the catchment area on the board were not met in a majority of cases. Moreover, most boards lacked the functional requirements for decision-making (i.e., carrying out the specific decision-making responsibilities of hiring the director, approving the budget, setting policy, and meeting at least once a month). This breakdown in implementation of the law is interpreted by the author as caused by dual problems of the needs for organizational adaptation and the need for power redistribution. Policy solutions would need to take both these causes into account. Incremental strategies alone are unlikely to create sufficient impact. Organizational development focused on building new models of governance and direct efforts to mobilize and empower citizens are suggested. The author concludes that government should work to strengthen citizen organizations. [Journal abstract, edited.]

**Comments:** An example of the kind of research undertaken in response to the requirements laid out in the Community Mental Health Centers Act (P.L. 94-63), this article offers good references to other articles, mainly from the late 1970s. Some examples of items from a survey of executive directors and board presidents are included, and the demographics of board members are documented as well. Lessons learned from this study regarding institutional resistance to full representation and participation on boards can be applied to parent participation on decision-making, advisory and policy-making bodies that pertain to children's mental health.

**DeWind, J. (1982). *The organizing of parents to support bilingual education*. New York: Columbia University, Center for the Social Sciences, Immigration Research Program. (ERIC Document Reproduction Service No. ED 235 296.)**

**Key Words:** bilingual education, minority family member participation, barriers to participation, developmental model of participation, research, advisory boards, community change, constituency building

**Synopsis:** This report describes bilingual education advocates' efforts to involve Hispanic parents in political activity. Extensive historical and community background is given. A typical developmental sequence of parent involvement is outlined, usually beginning with strictly educational activities, progressing to involvement with local parent advisory committees, and for some parents, moving on to participation in district, state, and national policy-making groups.

**Comments:** Much of the report is specific to the issue of bilingual education; however, some sections are useful in understanding barriers to minority family member involvement in policy-making bodies, and in devising ways to encourage such involvement and participation.

**Hausner, T., Johnson, F.T. & Sevick, J.R. (1982). Factors affecting the representation of minorities and the disadvantaged in health planning agencies. *Journal of Health and Human Resources Administration*, 5(2), 133-144.**

**Key Words:** minority family member participation, barriers to participation, demographics of advisory board members, health care, advisory boards, constituency building

**Synopsis:** Results from a study commissioned by the federal Office of Health Resources Opportunity (OHRO) are presented. The study's aim was to make a preliminary determination of factors affecting representation of minorities, women and other vulnerable groups on governing bodies of health system agencies. Historical background about consumer participation, documentation of the problem of under-representation of minorities and women on health system agency boards, and the methodology and findings of this OHRO study are all discussed. The article also considers the issue of "broad representation" on the staffs of local and state health system agencies, covering recruitment and selection of staff, the supply of "disadvantaged professionals," and the perceived effectiveness of minority staff.

**Comments:** Among the findings described in the article, two are especially relevant to parent participation on advisory boards. First, the authors found that the more sophisticated an agency's recruitment and nomination process, the higher its level of minority representation. Second, they report that the vast majority of board members from target groups in this study had similar characteristics--in terms of level of education, belonging to a respected profession, and relatively high income--when compared to non-minority members. Potential problems in selecting minority members and in maintaining their participation (essentially income-related factors like need for reimbursement, transportation difficulties or feelings of inferiority, which parallel the "barriers to participation" found in the literature on family/consumer participation on boards) are hypothesized, but are not confirmed by this study's findings.

**Lynch, E.W. & Stein, R.C. (1987). Parent participation by ethnicity: A comparison of Hispanic, Black and Anglo families. *Exceptional Children*, 54(2), 105-111.**

**Key Words:** special education, minority family member participation, barriers to participation, research, special education, strategies for effective participation, advisory boards

**Synopsis:** This article describes the results of a study of Hispanic parents' satisfaction with and participation in their children's special education program and compares their responses to those of African-American and Anglo families from an earlier investigation. This study found that Hispanic families tended not to be active participants. Identified among the major barriers which caused them to be less active were work schedules, lack of bilingual communication, and general communication problems.

**Comments:** Several aspects of the study design and findings are applicable to understanding and facilitating parent/family participation on boards. The study was conducted with in-home interviews by Special Education Parent Facilitators (SEPFs), who were trained and paid as paraprofessionals to provide support, information and training to other parents. The barriers to active participation across all ethnic and income groups included work conflicts, time constraints, transportation problems and child care needs, and these barriers represented the experience of the majority of families. Hispanic families indicated that holding bilingual meetings, selecting convenient times for parents, providing transportation, giving more advance notice of meetings and providing child care would help maximize participation. Black families listed

general communication problems with the schools as major barriers. Suggestions are given regarding ways to initiate involvement of families from diverse linguistic and cultural backgrounds.

**McCullagh, J.G. (1988). Challenging the proposed deregulation of P.L. 94-142: A case study of citizen advocacy. *Journal of Sociology and Social Welfare*, 15, 65-81.**

**Key Words:** Education for All Handicapped Children Act, P.L. 94-142, advocacy, research, special education, constituency building, legislative change

**Synopsis:** Public Law 94-142, The Education for All Handicapped Children Act of 1975, considered by many to be the most significant federal legislation for children in need of special education, was proposed for deregulation by the Reagan administration in 1982. This study examines actions taken by citizen advocates -- consumer/advocacy/parent (CAP) organizations and groups, parents, and other advocates for exceptional children -- who gave testimony in opposition to the proposed changes at public hearings held by the United States Department of Education in late 1982. The most controversial proposed rules were withdrawn on September 29, 1982, while the remaining proposed changes were not implemented. Citizen advocates' overwhelming presence at the hearings and their other activities were instrumental in defeating the administration's efforts at deregulation. [Journal abstract.]

**Comments:** This study drew upon the written testimony of 1,426 witnesses who submitted their statements to the U.S. Department of Education. The findings include discussion of the categories of witnesses (i.e., gender, parental status, children's special education classification, and whether witnesses identified themselves as representing an organization, profession or parents in general) and themes that emerged from their testimony. While not directly related to family involvement on policy-making bodies, this article adds weight to arguments for family participation in decision- and policy-making in general.

**Saylor, C.F., Elksnin, N., Farah, B.A. & Pope, J.A. (1990). Depends on who you ask: What maximizes participation of families in early intervention programs. *Journal of Pediatric Psychology, 15*, 557-569.**

**Key Words:** family member participation, strategies to increase participation, barriers to participation, early intervention, advisory boards

**Synopsis:** The two-part study reported on in this article investigated the types of procedures that might be useful in maximizing the participation of families involved in early intervention programs for young children with special needs children. Study 1 involved 64 professionals in the early intervention field who completed a survey describing 29 potential ways of maximizing family participation. Both respondent endorsement of actual or potential use of each method and respondent rating of perceived effectiveness of each technique were compiled and analyzed. The most highly rated and used methods were verbal praise and encouragement. Various types of written and resource materials were also rated highly and used widely. Tangible reinforcement -- the use of money, tokens, or concrete rewards -- was rarely used and was not expected to be an effective motivator. Study 2 involved 29 mothers of high-risk infants and toddlers currently in early intervention programs. This sample also rated the same 29 procedures, however, family members were much more likely to support the use of tangible reinforcers and logistical support (transportation, meals, child care, etc.). The authors discuss comparisons among respondents from both samples, consider implications of the findings, and make recommendations for needed research in this area in the future.

**Comments:** While focused on families involved in early intervention direct service programs, the results from this study may be generalizable to involvement of some family members in policy-making and advisory bodies. In particular, parental responses endorsing the use of tangible reinforcers and logistical support may be relevant to maximizing family member participation across settings.

**Sohng, S.S.L. (1992). Consumers as research partners. *Journal of Progressive Human Services, 3*(2), 1-14.**

**Key Words:** empowerment; research methodology, family member-professional collaboration, constituency building

**Synopsis:** Asserting the relevance of consumer empowerment to research, this review of a participatory research approach based upon an empowerment model demonstrates how empowerment principles can be implemented in social work research. It argues that a participatory, qualitative approach can avoid some of the drawbacks of traditional, positivist research models. Further, such an approach can result in more humane, rational, and liberating knowledge. [Journal abstract, edited.]

**Comments:** The principles discussed in this article are relevant in considering evaluation research design for projects or programs involving parents as policy-makers. The author makes a distinction between “traditional” and “participatory” approaches to research. A participatory approach involves shared ownership of the undertaking, is a mutually educative experience, and encourages activist attitudes and community-based change. Such principles fit with the “family-centered” approach that underlies efforts to involve parents on boards.

**Tarico, V.S., Low, B.P., Trupin, E. & Forsyth-Stephens, A. (1989). Children's mental health services: A parent perspective. *Community Mental Health Journal*, 25, 313-325.**

**Key Words:** research methodology, family member participation, Child and Adolescent Service System Program (CASSP), children's mental health, evaluation of service system, constituency building, community change

**Synopsis:** Parents of children with severe emotional and behavioral disturbances rarely have the opportunity to participate in the policy-making processes that affect their children's welfare. This study reports results of a survey utilizing a structured parent interview, developed as part of Washington State's Child and Adolescent Service System Program (CASSP). Thirty-five parents of children with emotional disorders provided information about their children's problems and service history. Respondents identified unmet needs and barriers to timely, effective intervention. The nature and quality of services received were examined in the context of CASSP service standards. The study confirmed that parents of children with emotional or behavioral disturbances can provide information rich in implications for system change. [Journal abstract, edited.]

**Comments:** Although the small, nonrandom sample precludes broad generalization of this study's findings, the study's methodology is useful for gaining insight into parents' viewpoints, and could be replicated on a larger scale. Specific results of the study included family members' desire for

comprehensive services for both children and their families, for greater individualization of services, and for increased public awareness of the need for children's mental health services. The article also implicitly supports the value of eliciting family members' input, since the information gathered was very useful in evaluating the quality of services received and in describing unmet needs of families.

**Vosler-Hunter, R.W. & Hanson, S. (1992). Parents as policy-makers: Challenges for collaboration. *Focal Point*, 6(1), Bulletin of the Research and Training Center on Family Support and Children's Mental Health. (Available from Portland State University, Regional Research Institute for Human Services, P.O. Box 751, Portland, Oregon 97207-0751, (503) 725-4040).**

**Key Words:** family member-professional collaboration, family member participation, research methodology, strategies for effective participation, advisory boards, personal strategies

**Synopsis:** Implications of parent-professional collaboration on policy- and decision-making boards and committees are examined. Qualitative research which explored parents' experiences with participation on boards is outlined, and illustrative quotes from parents are included. Findings from structured group interviews (focus groups) are summarized, including a listing of comments regarding policy-making skills for parents, tips for surviving on the board, and strategies for boards to consider when recruiting family members. The article concludes with an assertion of the value of parent-professional collaboration on boards.

**Comments:** This article offers a concise introduction to key issues in, and approaches to, parent participation on boards and committees. It includes a description of the "Families in Action Project," a five-year study aimed at developing, testing and disseminating strategies and materials that incorporate skills and knowledge needed for effective family member participation on committees, boards, and other decision- or policy-making bodies.



## **PRACTICE: STRATEGIES AND EXPERIENCES REGARDING PARTICIPATION**

**Apolloni, T. (1985). Effective advocacy: How to be a winner. *Exceptional Parent, 15*(2), 14-19.**

**Key Words:** advocacy, family member participation, advisory boards, personal strategies, service system reform, legislative change

**Synopsis:** This highly practical article explains and illustrates a four-stage “self-advocacy cycle.” The cycle includes: (a) targeting the needs of the individual or family, and identifying the service agencies responsible for addressing them; (b) preparing to work with professionals in order to develop approaches to meet those needs; (c) influencing decision-makers within human services agencies to use the preferred approaches; and (d) following up to insure that professional/self-advocate agreements are carried out. The author includes specific examples of suggested questions, sources of information, and key issues for advocates to consider for each stage.

**Comments:** Parent-advocates serving on decision-making bodies may find Apolloni's discussion of “influencing decision-makers” and “maintaining a paper trail” particularly useful.

**Cromwell, H.S., Howe, J.W. & O'Rear, G. (1988). A citizen's coalition in mental health advocacy: The Maryland experience. *Hospital and Community Psychiatry, 39*, 959-962.**

**Key Words:** advocacy, legislative change, community change, adult mental health consumer participation, family member participation, family member-professional collaboration, constituency building

**Synopsis:** In July 1983, four statewide Maryland citizens organizations formed a coalition to advocate for persons with mental illness. The chief focus of their advocacy was on making a place in the community for citizens with long-term mental illness. The coalition's rules were simple: to advocate jointly on issues on which they all agree and to not mention their disagreements in public. With a paid lobbyist, the coalition's advocacy helped produce significant financial and programmatic gains for Maryland's citizens affected by mental illness. The authors define “systems advocacy” as broad-based social action that influences public

policy and practices through legislation, public education and systemic reform.

**Comments:** This article provides specific information about how the coalition of four independent groups was formed and maintained without compromising the autonomy of any one group. The coalition included a group run by adult consumers, a group run by family members, and two groups with a provider base.

**Fawcett, S.B., Seekins, T., Whang, P.L., Muiu, C. & Suarez de Balcazar, Y. (1982). Involving consumers in decision-making. *Social Policy*, 13(2), 36-41.**

**Key Words:** consumer participation, evaluation of service system, constituency building, community change.

**Synopsis:** Beginning with arguments for including the perspective of consumers when assessing an institution's performance, the article goes on to describe the use of the Concerns Report Method, as systematic data collection process for agencies to use with citizens to identify strengths and problems in agencies and the community. Citizens select issues to be studied and interpret the results. A ten-step process for implementation of the method is described and uses of the information collected in the report are discussed.

**Comments:** This article offers both rhetorical justification for family member participation in program evaluation and a practical, explicit process that family members who are activists can use to undertake such evaluation. While the Concerns Report Method itself is somewhat unsophisticated--it is essentially a consumer survey--the step-by-step format enhances its utility.

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

**Key Words:** special education, family member-professional relationship, professional attitudes, advisory boards, personal strategies

**Synopsis:** The author presents, in a sarcastic style, ways parents of children with disabilities are not recognized by professionals.

**Comments:** Awareness of the "therapizing," patronizing and tokenistic attitudes and actions described by Gartner may prepare family members participating on boards to recognize and effectively confront such actions if they occur. The article is both entertaining and thought-provoking.

**Hunter, R.W. (1994). *Parents as policy-makers: A handbook for effective participation.* Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health. (Available from Portland State University, Regional Research Institute for Human Services, P.O. Box 751, Portland, Oregon 97207-0751, (503) 725-4040).**

**Key Words:** family member participation, strategies for effective participation, advisory boards, advocacy, personal strategies

**Synopsis:** This practical handbook provides information and strategies concerning parent involvement on boards and advisory committees specific to families of children with emotional disorders. Based on information collected from a national project assessing family participation on boards and committees, the handbook provides reader-friendly descriptions of the policy-making process and practical strategies for meaningful family participation. The manual is divided into four sections: (1) *Understanding the Board Process*, describes different types and functions of policy-making bodies; (2) *Strategies for Effective Participation*, includes suggestions on improving communication skills, "how to's" of leading and participating in meetings, dealing with conflict, and developing an assertive style of participation; (3) *Organizing as Advocates*, offers information on how family support and advocacy organizations can influence the system, recruit and prepare members for policy-making roles, and develop strategic plans to effect system change; and (4) *Resources for Decision-Making*, provides a series of information sheets on children's mental health.

**Comments:** Enhancing its practical approach, this handbook includes a number of quick reference checklists summarizing major questions or points made in the text. Valuable for both parents and professionals who participate on boards, *Parents as Policy-Makers* is a useful resource for both training and ongoing participation.

**Issues and Advocacy Committee of Parent to Parent of Florida, Inc. (1989).**  
*Advocacy through parent power via understanding the legislative process and networking.* (Available from Parent to Parent of Florida, 621 Kraft Avenue, Panama City, FL, 32401.)

**Key Words:** advocacy, legislative change, community change, constituency building

**Synopsis:** This handbook, set up in outline fashion, provides information and a step-by-step process for individual or group advocacy with a particular state legislature.

**Comments:** Written specifically for parents working with the Florida legislature, the ideas and methods laid out in this handbook have potential for nationwide application. The authors include a list of "Ten Commandments for Successful Living with your Legislator" that make valid points in a humorous way.

**Lucky, L. & Gavilan, M. (1987). Advisory committees: Making them effective.**  
*Exceptional Parent, 17(6), 24-30.*

**Key Words:** special education, evaluation of service delivery, advisory boards, family member-professional collaboration

**Synopsis:** The authors present effective ways in which an advisory committee ensures appropriate services for children with disabilities in one Florida school district.

**Comments:** The advisory committee used as a model in this article is made up of 25 members, 15 of whom are parents. It is chaired by parents as well. Successful approaches to problem and issue identification and resolution are described, and examples of the committee's major accomplishments are given.

**Mayer, J. (1994). From rage to reform: What parents say about advocacy.**  
*Exceptional Parent, 24(5), 49-51.*

**Key Words:** advocacy, developmental model of participation, barriers to participation, experiences of participation, experiences of, service system failures, personal strategies, advisory boards, constituency building

**Synopsis:** This article describes the process many parents of children with special needs have gone through, a process whereby families move from anger to personal and public advocacy. Learning from listening to parents' accounts of encountering barriers to accessing needed supports and services, Mayer points to becoming involved in a family support group as a key factor in moving beyond unfocused rage. "Personal advocacy" is seen as a springboard into "public advocacy" for some parents, and the benefits and costs of such involvement in policy-making are highlighted. The need to consider the impact of public advocacy on the family is stressed, and the advice of experienced parent-advocates is offered.

**Comments:** The author is herself the parent of two teenagers with special needs. Replete with the voices of family members who have "walked their talk," this article makes a compelling statement for involving families in advocacy and policy-making.

**Rissmeyer, D.J. (1988). Involving patients, relatives and community mental health professionals in the administration of a state hospital. *Journal of Mental Health Administration, 15*(1), 10-14.**

**Key Words:** evaluation of service delivery, family member-professional collaboration, adult mental health consumer participation, family member participation, advisory boards

**Synopsis:** This article describes the Western State Hospital Community Interface Panel, an administrative advisory panel composed of former patients, relatives of patients, and community mental health professionals. The purposes served by this panel are to increase administrative lines of communication with those persons who are most capable of providing appropriate feedback on inpatient programs, of sharing viewpoints on legislative and state policy issues, and of working toward enhancing the general community hospital collaboration characterized as a "single system of care." [Journal abstract, edited.]

**Comments:** The panel described in this article provides one working model of family participation on a policy-making body.

**Tropman, J.E. (1987). Effective meetings: Some provisional rules and needed research. *Social Work with Groups*, 10(2), 41-55.**

**Key Words:** participation, family member, participation, strategies for, advisory boards, personal strategies

**Synopsis:** This article builds on the author's qualitative research with people who have reputations as good group decision-makers. The prevailing American views that meetings are inconsequential and individuals make most decisions alone is critiqued. Eleven "Rules of Meetings," developed through the author's and others' research, are described. Put into practice together, use of these rules can save time, create an improved meeting climate, and result in a higher-quality decision-making process. Suggestions for experimental and field-based testing of these approaches are offered as well.

**Comments:** The need to avoid wasting participants' time and energy commends these "Rules of Meetings" for consideration. Careful preparation, sound organization, and good communication of relevant information are hallmarks of the process Tropman describes. Family members and professionals involved in meetings can benefit from understanding and using these principles.

**Trupin, E., McDermott, J. & Forsyth-Stephens, A. (1989). Maximizing the role of state legislators in the development of public mental health policy. *Hospital and Community Psychiatry*, 40, 637-638.**

**Key Words:** advocacy, family member-professional collaboration, legislative change, service system reform

**Synopsis:** Most of this article is devoted to outlining four basic tactics for mental health professionals to use in becoming involved in state politics and influencing state legislators. The authors also include suggested approaches to educating legislators about mental health issues.

**Comments:** This article presents information aimed at mental health professionals working with state legislators. Emphasis is also placed on advocacy by family and consumer groups. The basic tactics can be readily adopted by all groups.

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

**Key Words:** family member-professional collaboration, family member participation, strategies to increase participation, benefits and costs of participation, evaluation of service system, community change, constituency building, personal strategies

**Synopsis:** An historical view of why parents are not more involved in positive collaboration with professionals is presented. The authors consider the needs and issues faced by families of children with severe emotional problems. The Family Input Program in Kansas is described as an example of one way to identify parents and bring them together in groups. Parents are identified through schools, mental health clinics and private providers. The process of setting up meetings is outlined, including ways to invite parents and advertize meetings. A facilitator from the state mental health agency chairs the meeting, identifies parents as experts, and records data (with parents' informed consent). At the second meeting the data is shared and reviewed. If the parent group shows an interest, assistance is given for future group meetings.

**Comments:** The authors report that such meetings have a positive impact on parents, offering a forum for support and advocacy, as well as enabling parents to contribute key information and feedback to the mental health system. The positive impact on the state mental health agency is noted, too. Taking the perspective of parents into account is vital, for it is parents who have daily experience of the needs of their children and critical awareness of the services offered in their communities to meet those needs. While not a substitute for involving family members directly on policy-making bodies, this Kansas experiment points out the value of family member participation as a general principle, and offers one model for supporting parents and improving the system of care.



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