

Topical Discussion:



Evidence-Based Practice Controversies Within the Accountability Movement

Shelley Spear, PhD

Albert Duchnowski, PhD



April 2, 2007



Today's Objectives:

- Examine different perspectives on the accountability/evidence-based practices movement.
- Discuss the implications of the EBP movement for children, youth, families, and family organizations, as well as the family movement and the research community.

April 2, 2007

Shelley Spear

Who I am is important to what I will say:

- White female
- Not educated as a “scientist”
- Public mental health services consumer
- Advocate for family organizations

*Statewide Family Networks
Technical Assistance Center*



April 2, 2007

Why a movement toward “evidence-based practices”--what were we doing before?

- Split between research and practice
- History of practice design by professional consensus rather than controlled research
- Tradition of thinking in terms of access to programs not achievement of outcomes*

*This slide is taken from a presentation by Bill Carter, California Institute of Mental Health, Monmouth, OR, 2004.

April 2, 2007

What About the Family Movement?

- **Can we--and policymakers--support two movements?**
 - Movement in the Provision of Public Services
 - Social Movement
- **Why not just infuse the EBP movement with family movement values?**



April 2, 2007

Evidence-Based Practices: Definitions

Problems:



- What is evidence?
- What is a practice?
- Multiple public service definitions—some focused only on accountability.



April 2, 2007

Research Process: Where Do We Start?

Hypothesis?
Thesis?

We hold these truths to be **self-evident**, that all [people] are created equal, that they are endowed by their Creator with certain inalienable Rights, that among these are Life, Liberty and the pursuit of Happiness."

April 2, 2007

Research Issues to Consider from a Family Member's Perspective

- Appropriate outcomes for EBPs should be based on realistic goals that consumers and families value.
- Some treatments have been shown to cause harm.
- Being free of "symptoms" but living in a residential setting is not a "preferred outcome."



April 2, 2007

Family Organization Values: Holding Our Ground

To what degree is the EBP movement consistent with family organization (and SOC) values?

1. Comprehensive and coordinated services
2. Meet the immediate and anticipated needs of every child and family
3. Family-driven programs and services
4. Strength-based, individually tailored, and culturally apt.



April 2, 2007

Family Organization Values: What do families value the most?

Even when families know about EBPs, they emphasize pressing concerns not related to treatment options, including:

- Improving the System of Care culture
- Improving access
- Finding sufficient psychiatry time
- Setting standards
- Increasing consumer involvement in service planning
- Decreasing the use of residential treatment services


Participants rarely mentioned incorporating EBPs as one of their top priorities. (Hurlbert, 2003)



April 2, 2007

Choice: Mandating EBPs

- Isn't it obvious that government should mandate the use of effective practices?
- Family organizations want EBPs to be available to ALL families and children as a choice.



April 2, 2007

Family Organization Values: Potential Areas of Conflict

- Focus of research and treatment: diagnosis or child and family.
- Will children and families for whom EBPs do not work will be blamed for the lack of positive outcomes?



April 2, 2007

Not Just Practices— Systemic and Social Solutions



- The Surgeon General's Report: "Racial and ethnic minorities in the United States face a social and economic environment of inequality that includes greater exposure to racism and discrimination, violence, and poverty, all of which take a toll on mental health."
- Some are suggesting: bulk of funding should be mandated to go to programs that deliver EBPs.
- What about access to and use of services?

April 2, 2007

Not Just Practices— Systemic and Social Solutions

Exclusive concentration on families as focus of solutions:

- Implies that children and families are sources
- Ignores environmental targets of interventions (system reforms, poverty, discrimination, and stigma)

Solutions include policies that close economic gaps

- Individuals with Disabilities Education Act
- Section 8 housing vouchers
- Earned Income Tax Credit (Alegria, M., et al, 2003)



The income gap continues to increase.

April 2, 2007

Policymaking: Effects on Family Organizations

- Funding mandates and policy based on accountability alone may undermine many family organizations.
- What about the resources, services, and supports that don't fit under the umbrella of evidence-based practices?
- FO practices: as likely to lead to positive outcomes? (See chart.)
- This year's monograph is a lit review of practices like those of SFNs. (See monographs.)



April 2, 2007

THE ROLES OF FAMILY ORGANIZATIONS IN THE EVIDENCE-BASED PRACTICES MOVEMENT



United Advocates for Children of California

Staff:

Senior Writer/Editor: Shelley Spear

Director: Jennifer Clancy

Contributing Writers: Charles Anders, Roberto Ramos, Sireyia Ratliff, and Gayle Wiler

Copyediting/Layout:

Sandra McDonald

Rebecca Mitchell



Thanks to the following individuals for their contributions to the monograph:
Hugh Davis, Robert Friedman, David Gray, Terry Halwes, Nate Israel,
Pat Solomon, and Quinn Sosna-Spear.

This monograph was developed by United Advocates for Children of California.

Table of Contents

I.	Introduction: What Are Evidence-Based Practices and How Do They Relate to Family Organizations?.....	1
II.	Issues and Controversies: Why Should Family Organizations Examine the Evidence-Based Practices Movement?.....	3
A.	Perspectives on Science and Research Methodology: How Might Conceptions of Science and Research Affect the Evidence-Based Practices Movement?.....	4
1.	Ways of Viewing the World	4
2.	Randomized Controlled Trials and Observational Research	5
3.	Internal Validity and Control Groups	9
4.	External Validity.....	11
B.	Cultural Competence: How Should Cultural Difference Affect the Study and Utilization of Evidence-Based Practices?.....	13
1.	Access to Evidence-Based Practices	13
2.	Access to the Research Process	14
3.	Effectiveness and Appropriateness of Practices and Their Study.....	15
4.	Lack of Trust within Diverse Communities	16
5.	Systemic and Social Solutions Not Related to Practices	16
C.	Family Organization Values: To What Degree is the Evidence-Based Practices Movement Consistent with Family Organization Values?	20
1.	Values and the Definition of Evidence-Based Practices.....	20
2.	Family-Driven, Strength-Based, Individualized Care.....	21
3.	System of Care Values and Structure.....	24
D.	Evidence-Based Practices and Policymaking: How Might Family Organizations Influence Government and Service System Mandates Regarding Evidence-Based Practices?	25
1.	Considerations about Mandates to Include Evidence-Based Practices	25
2.	Potential Effects of Policy Mandates on Family Organization Practices	27
III.	Conclusion: Expanding the Research Base	30
IV.	References.....	31

Abstract: *This monograph discusses issues related to the evidence-based practices movement as they apply to family organizations. Specifically, it examines the scientific and research grounding of the movement and sets out the ways in which the goals of cultural competence and the movement may conflict. In addition, it explores how the EBP movement may have the potential to be inconsistent with the values of family-driven, individualized, and strength-based care. Finally, the monograph addresses the ways in which government policy related to the EBP movement can affect and be affected by family organizations, and the potential problems that may arise from policy mandates regarding the implementation of evidence-based practices. The monograph is intended to provide family organizations with information that will assist them in forming their own policy positions.*

I. Introduction: What Are Evidence-Based Practices and How Do They Relate to Family Organizations?

While a great deal has been written about the implications of the evidence-based practices movement in relation to clinicians, mental health service systems, and mental health policy, little has addressed the children and families who are the target of services, and almost nothing has discussed family organizations. At the same time, “the evidence-based practices train has left the station,” as one family advocate has so aptly remarked. In order for family organizations to influence the direction of that speeding train, they will need to move quickly and decisively. The central purpose of this monograph is to provide information about the issues in the evidence-based practices movement that are directly relevant to families and family organizations, and to assist family organizations in developing policy positions. Family organizations, administrators, clinicians, advocates and others agree that the most effective mental health treatments should be available to all children and families. In order to achieve this goal it will be important for family organizations to monitor the evidence-based practices movement and make their voices heard. The goals of culturally competent, family-driven, strength-based, and individualized care will not be achieved unless families and family organizations are guiding the process.

Over the past several years, national interest in evidence-based practices for mental health has intensified. The term “evidence-based practices” refers to interventions for which there is consistent scientific evidence showing improved child and family outcomes.¹ It derives from the term “evidence-based medicine,” which was coined in 1990 in relation to general medical practices. Since then, the systematic use of research evidence in clinical decision-making has expanded to the field of mental health. However, the Surgeon General’s Report on Mental Health² (1999) found that treatments demonstrated by scientific research to be effective for even the most serious of mental illnesses are still not being widely implemented in most community settings. As the prominence of evidence-based practices for children’s mental health increases, family organizations can benefit from taking a role in the processes and policymaking regarding their development, research, implementation, and evaluation.

¹ Drake, R. E., et al. (2003). Strategies for implementing evidence-based practices in routine mental health settings. *Evidence Based Mental Health*. February 6 (1): 6-7.

² U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.

In part the evidence-based practices movement is related to the need for government agencies to make sure that the organizations they fund are promoting and providing effective services. According to P. Brounstein, “[G]overnment agencies [are] charged with bridging the gap between research and practice towards greater accountability in public and private sector funding.”³ He explains that part of his goal at the National Technical Assistance Center at Georgetown is to “help prepare the prevention community for the new performance results-oriented environment.” This goal has become characteristic of most government-funded programs, and a core element of this goal is the promotion of evidence-based practices.

This monograph focuses the national discussion of evidence-based practices in the field of children’s mental health on controversial issues that are critically important to family organizations. *The Roles of Family Organizations in the Evidence-Based Practices Movement* begins by looking at the connection between different ways of seeing the world and conceptions of science. More specifically, it examines the limitations of standard research methodology in relation to the development of evidence-based practices. Then the monograph explores the problematic implications of the evidence-based practices movement for the cultural competence of children’s mental health services, and by extension, family organizations. It discusses potential conflicts between the evidence-based practices movement and family organization values in relation to definitions of terms, family-driven, strength-based, individualized care, and the conception of system of care. Finally, the monograph addresses vital concerns about policy mandates.

The body of the monograph is divided into the following sections:

- Research Methodology
- Cultural Competence
- Family Organization Values
- Policy Mandates

³ Brounstein, P. (2003). SAMHSA’s national dissemination system for model prevention programs. *Data Matters: 6, 2,12*. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

II. Issues and Controversies: Why Should Family Organizations Examine the Evidence-Based Practices Movement?

Family organizations all over the country are involved in creating position statements regarding evidence-based practice policies, exploring the ways existing evidence-based practices can be made available to all families in their states, and/or developing means for ensuring that families have the knowledge they need to direct care plans that may include evidence-based practices. The movement toward evidence-based practices has developed according to the following three premises. First, children with serious emotional and behavioral disturbances should receive the best care possible. Second, the care received by many children is not effective. Finally, research on the effectiveness of children's mental health care practices and the application of this research will improve children's mental health care.⁴

Achieving the goals of the evidence-based practices movement poses complex challenges related to both implementation and values. Implementation challenges generally have to do with funding, the availability of willing, trained, and diverse service providers, and time. In 2003 the National Evidence-Based Practices Project published findings that describe the stages of and necessary elements for successful implementation. R. E. Drake reports that "education alone is ineffective at changing health care practices. Changing complex programs requires ... enhancing motivation, providing adequate resources, increasing skill development and removing environmental constraints. Second, change occurs over time. Implementation strategies can be divided into three stages: a) motivational or educational interventions to prepare for change; b) enabling or skill building interventions to enact a new practice, and c) reinforcing structural or financing interventions to sustain change. Third, greater effort and involvement by stakeholders increases success."⁵

Along with those related to implementation, challenges connected to evidence-based practices involve the values of service providers, families, and family organizations. Drake continues, "[P]rogram implementation is most likely to be successful when it matches the values, needs and concerns of practitioners." It is also more likely to be successful when the values of families and family organizations, particularly those related to culturally competent children's mental health services, inform the process of development and implementation at all levels.

Currently evidence-based practices are being viewed by many administrators, researchers, providers, and others as the panacea for children's mental health woes, and as a pathway to culturally and linguistically competent, family-driven care. Despite this enthusiasm, the evidence-based practices movement is generating vigorous controversy related to cultural and linguistic competence and family organization values. Concern is escalating about the compatibility of culturally competent attitudes, behaviors, and skills with a number of evidence-based practices. It is clear that some aspects of the evidence-based practices movement have the potential to conflict with the values and principles that family organizations support.

Profile of an Evidence-Based Practice: The Incredible Years

"The Incredible Years" involves three curricula for parents, teachers, and children. The program is intended to promote emotional and social competence and to prevent, reduce, and address behavioral and emotional problems in young children (2 to 8 years old), who may be at greater risk for developing substance abuse problems, dropping out of school, and engaging in violence. Some family organizations are currently offering or training to offer this practice.

⁴T
R.
A.
D.
<v
⁵ Drake, R. E., et al. (2003). Strategies for implementing evidence-based practices in routine mental health settings. *Evidence Based Mental Health*. February 6 (1): 6-7.

A. Perspectives on Science and Research Methodology: How Might Conceptions of Science and Research Affect the Evidence-Based Practices Movement?

The evidence-based practices movement is founded on a general conviction within the field of children's mental health that scientific research can greatly improve the effectiveness of the care received by children and families. At the same time, the practice of science, particularly in the form of research on children's mental health, is shaped by the beliefs, attitudes, and values of the cultures in which research is taking place.

1. Ways of Viewing the World

In a multicultural world there are competing scientific models of observing, investigating, and explaining natural phenomena. While many scientists of the past tended to assume that their work was objective and free from the influence of the values of the larger culture and their own biases, current scientists generally agree that science is a socially constructed discipline and thus inherently influenced by the values, attitudes, and desires of the broader community. In recent decades, many scientists and scholars from all over the world have begun to examine the influence of traditional values and principles on the standard scientific model, and to look at alternative models premised on different values. Contrasts between a standard model of science and an alternative model illustrate the substantial influence of worldviews on the way evidence-based practices are conceived.

Standard Model

Contrasts between a standard model of science and an alternative model illustrate the substantial influence of worldviews on the way evidence-based practices are conceived.

For the last several centuries, world science has been highly influenced by a model that has been called "western" due to its origins in Ancient Greek and European culture. Aristotle, whose philosophy has had a major impact on scientific thought, held that since "nature makes nothing without some end in view, nothing-to-no purpose, it must be that nature has made [animals and plants] for the sake of man."⁶ In this model, the natural world is separate from humans and subject to their control. The universe is seen as being made up of individual pieces that should be examined separately. Time is assumed to be linear and progressive: there was a beginning of the universe and there will be an end, and the scientific developments of humankind lead to the progress of civilization. The scientific model based on this worldview entails developing a potential answer to a question about an individual phenomenon, isolating, as much as possible, the individual phenomenon to be studied, and manipulating the phenomenon by making changes to it or its environment. Then the phenomenon is analyzed to see what, if anything, has resulted from the manipulation, and a conclusion about the original answer to the question is generated. This model can be referred to as "standard" because it is presented as the standard in most primary and secondary school curricula and is most familiar to the public.

The most respected research method in mental health comes out of the standard research model. The alternative model, however, may often be more compatible with family organization values and the research of family organization practices.

⁶ Aristotle

Alternative Model

In opposition to Aristotle, who asserted that humans should control nature, Chief Seattle, a 19th century leader of the Duwamish tribe of Native Americans, stated, “The earth does not belong to man; man belongs to the earth. All things are connected.”⁷ An alternative cultural perspective, which is characteristic of a large part of the world including diverse American communities sees time as having no beginning and no end. In addition, the developments of civilizations are not always regarded as progressive. In this model Earth is a web of life, and each element is inseparable from all the other elements. Humans are a part of the web and should try to maintain its balance and integrity as they fulfill individual and societal needs. Because the world is a web of relationships, understanding the world primarily consists of observing connections and correlations. Scientific thought processes are primarily inductive, proceeding from particular data to tentative conclusions. The alternative model involves beginning with a question about a phenomenon and related phenomena, observing connections, relationships, and correlations involving the phenomena, and coming to a provisional conclusion about the original question. This conclusion, which is essentially a larger understanding of connections, relationships, and correlations, is expected to be modified over time as more observation is conducted and more data is collected.

Based on centuries of observation and experimentation, the science of many Native American/American Indian cultures exemplifies the alternative model. It is premised on a values system with different assumptions than those that underlie the standard model. Following is a list of those values, taken from a bulletin at the Smithsonian Institution:

1. Nature is viewed as sacred.
2. Humans are part of the web of life.
3. Humans should live in harmony with nature.
4. The entire world is viewed as being alive.
5. Technology should be low impact.⁸

It is very important to note that neither the standard nor the alternative scientific model exclusively informs the science of contemporary cultures. In fact, most current scientists in fields like chemistry, physics, and astronomy use methods that more closely resemble the alternative model described above than the standard model. The distinctions between the two are significant to family organizations’ conceptions of science because the most respected research method in mental health comes out of the standard research model. The alternative model, however, may be more compatible in many circumstances with family organization values and practices.

2. Randomized Controlled Trials and Observational Research

Assessing the strengths and weaknesses of different research methods, their cultural competence, and their appropriateness to the study of family organization practices can best be accomplished by exploring how those methods operate.⁹ Currently, virtually all children’s mental health practices that are given the highest “evidence-based” ratings have been studied

⁷ Chief Seattle. Environmental statement. In *Writing About the World*. Ed. S. McLeod, J. Jarvis, and S. Spear. New York: Thompson, 2005, 695.

⁸ Cobem, W., and C. Loving. (2004). Defining science in a multicultural world: implications for science education. An Interactive Session on Defining Science Within Science Education from Multicultural and Universalist Perspectives. Department of Education, University of Michigan. <<http://www.wmich.edu/slscsp/14.html>>.

⁹ This monograph will discuss research methods as they are generally conducted in the field of children’s mental health. It is important to remember that all research methods can be adapted to improve cultural competence and appropriateness to families and family organizations.

using randomized controlled trials.

Assessing the strengths and weaknesses of different research methods, their cultural competence, and their appropriateness to the study of family organization practices can best be accomplished by exploring how those methods operate.

Randomized Controlled Trials

The research process of randomized controlled trials begins with the development of a hypothesis or “theory.” For example, the theory might be: The “SBW Parent Training”¹⁰ will improve the academic performance of children with Oppositional Defiant Disorder. The next step is to articulate the ways in which the desired outcome will be achieved (which will become the “manual” for others who may use the training in the future). At this point, individual families are identified as research subjects. These families might be selected from among a pool of families who share particular characteristics, for example, a requirement of focusing on a child with a single diagnosis. Once they are screened, families are randomly assigned to an experimental or a control group. The goal of random assignment is for each group to have the same number of subjects without the possibility of bias influencing the choice of which subjects go into which group. The “SBW Parent Training” is then given to the experimental group only. The training is examined to make sure it is done in the way it is intended, that is, with “fidelity” to the model. The control group is given no training, but might be given usual care.

The research then involves the collection of data about the outcomes of the training. Data may be collected at any number of times during and/or after the training. The same data is collected about the control group. Then the data is compared across groups. If the experimental group is shown to have better outcomes than the control group, the training is assumed to be likely to have caused those outcomes. If outcomes are not significantly different between groups, the training is assumed to be no better or worse than the control situation. If the research group has worse outcomes than the control group, the training is assumed to be harmful. The evidence base of the “SBW Parent Training” is strengthened by having similar positive results occur when it is conducted repeatedly by various researchers in a wide variety of places with similar target populations. This method of research, the randomized controlled trial (RCT),¹¹ is currently the most highly valued method in establishing evidence-based practices,¹² not only in the field of children’s mental health, but in a wide variety of other fields related to the social sciences. It can be an extremely effective method of testing a specific theory.

Currently, virtually all children’s mental health practices that are given the highest “evidence-based” ratings have been studied using randomized controlled trials.

Observational Research

Given the same intended outcome as the one described above--the improvement of the academic performance of a child with Oppositional Defiant Disorder--observational methodology (more characteristic of the alternative research described earlier) might involve

¹⁰ This is a fictitious training label.

¹¹ For a more detailed description of a randomized controlled trial, see the following website: <<http://servers.medlib.hscbklyn.edu/ebm/2200.htm>>.

¹² For a discussion of how various methods of research are valued, see *Guide to Research Methods: The Evidence Pyramid* at <<http://servers.medlib.hscbklyn.edu/ebm/2200.htm>>. See also Chambless, D., and Ollendick, T. (2001) Empirically Supported Psychological Interventions: Controversies and Evidence. *Annual Review of Psychology*, Annual, 2001.

the following process. A child with Oppositional Defiant Disorder whose academic performance is poor is closely observed by a researcher in the child's actual settings (*i.e.*, at school, in an after-school program, and at home). The researcher takes detailed notes about the child in each of the settings, focusing on the child as a whole, (*i.e.*, his/her academic behavior, as well as his/her social behavior; in addition, data might be collected about the behavior of those with whom the child interacts, and the child's environment). The data is then analyzed by the researcher to find indicators of connections between academic performance, the child's behavior, the behavior of others, and the environment itself.

As a result of analysis of the data, changes (interventions) might be made involving the child, others, and/or the environment. A specific intervention would be identified, and if necessary, modified to be appropriate to the particular child's observed needs, the needs of others within the child's environment, and the environment itself. Afterward, the researcher would again observe the child's behavior to see if improved outcomes had resulted from the intervention.¹³ The process of observing, making connections, and intervening may continue for as long as is desired, with any conclusions about the effectiveness of interventions being provisional. This method of research, which can be loosely described as "observational," resembles the formalized process of the "case study," which is generally assumed by the mental health research community to be somewhat valuable, but has not been the basis of practices that receive the highest evidence-based ratings.¹⁴ Conducting a series of case studies (a "case series") can significantly increase the evidence base of interventions based on this kind of research, especially when similar positive results occur in a wide variety of places with various researchers.

These differences have important implications for the cultural competence of children's mental health research, as well as the appropriateness of research methods for the study of family organization practices.

Both of the research processes described above can be enormously useful, but their strengths and weaknesses are different. In addition, differing values can be attached to the choice of one method over the other. These differences have important implications for the cultural competence of children's mental health research, as well as the appropriateness of research methods for the study of family organization practices.

¹³ This process is similar to the Participatory Action Research Model, which consists of planning, implementing an intervention, observing, reflecting, and beginning the process again. See Turnbull, A., et al. (1998). Participatory action research as a model for conducting family research. *Journal of the Association for Persons with Severe Handicaps*: 23, 178-188.

¹⁴ In addition to simple observation, an alternative research model might include such methods as interviewing, video and audio taping, and surveying.

The table below compares various characteristics of randomized controlled trials and observational research. The chart compares the two methods as they are generally conducted, rather than according to ideal applications of the research methods.

<p style="text-align: center;">A Comparison of Two Research Methods For Studying Children’s Mental Health Practices</p>		
Areas of Comparison	Randomized Controlled Trials (RCTs)	Observational Research
Focus of Research: Does the research focus on groups of subjects or on individual subjects?	More likely than observational research to be focused on groups of research subjects.	Less likely than RCTs to be focused on groups, more likely to be focused on individual subjects.
Research Setting: In what kind of setting is the research conducted?	More likely to be conducted in controlled, laboratory-like settings (or in relatively uncomplicated “real world” settings) than observational research.	Can usually be more easily conducted in “real world” and complex settings (<i>i.e.</i> , multiple diagnoses, diverse household structures) than RCTs.
Diverse Research Subjects: How easily can the research be conducted with diverse research subjects?	More problematic to select subjects from among widely diverse groups than observational research.	Research subjects can be more easily selected from among widely diverse groups.
Focus of the Intervention: What is the focus of change: an individual child and family or the child’s environment (the child’s immediate surroundings, some aspect of the service system, or the larger community).	Generally focused on individual children and their families, rather than on the environment, the service system, or the community.	More likely than the RCT to be focused on some aspect of the child’s environment, the service system, or the community.
Focus on Diagnosis: To what degree does the research involve selecting and grouping children according to the pathology of their diagnoses?	Children are almost always selected as research subjects and grouped according to their diagnoses.	Children are less likely than with RCTs to be selected or grouped according to diagnoses.
Cost of Research: What are the comparative costs of the two methods?	Likely to be considerably more expensive than observational research.	Generally much less expensive than RCTs.
Researchers: Who is able to conduct the research?	More likely than observational research to require professional researchers.	Less likely than RCTs to require professional researchers.

Understanding the implications of the comparisons described in the chart is essential to making informed decisions about research methods. While researchers, as well as service providers, administrators, and others, have often been trained to value the characteristics of randomized controlled trials, family organizations may often attach more weight to the characteristics of observational research. Observational research may be more appropriate to individual children and families who live in diverse household structures and deal with multiple mental health diagnoses. It may be more supportive of individualized, strength-based, and family-driven care. In addition, it may be more likely to examine the larger context of the child and family and uncover potential interventions that focus on aspects of their larger environment. Moreover, observational research often may be more easily conducted and less expensive than randomized controlled trials, and it can potentially be conducted by specifically trained family organization staff and/or family members. For these reasons, family organizations may want to consider promoting observational research as a highly valued source of evidence within the evidence-based practices movement.

Research that is done in relation to a simple diagnosis, in a generalized cultural context, and within a “laboratory”-like setting may not be relevant to children and families who cannot be studied in these circumstances, who constitute a considerable segment of family organizations’ target populations.

In addition, although the standard research model may be a very effective means of testing a theory, the circumstances in which this approach is appropriate are limited. If a practice can only be labeled “evidence-based” when research is highly controlled, research that is done with small groups of subjects in complex circumstances will not tend to meet evidence-based standards. According to R. Espiritu, “The standards of evidence-based practices often exclude the few existing efficacy studies on specific sub-groups due to their small sample size. As Bernal & Scharron-del-Rio (2001) point out, the criteria of efficacy research often emphasizes internal validity (whether observed changes can be attributed to interventions) over external validity (generalizability).”¹⁵ Research that is done in relation to a simple diagnosis, in a generalized cultural context, and within a laboratory-like setting may not be relevant to children and families who cannot be studied in these circumstances—a considerable segment of family organizations’ target populations.

3. Internal Validity and Control Groups

Controversy involving evidence-based practices research is connected to specific elements of research design. Internal validity, which looks at cause and effect relationships, has to do with assessing the effectiveness of mental health interventions. It looks at the degree to which a practice, rather than other possible factors, can be said to have resulted in an outcome.¹⁶ There are two major concerns when looking at internal validity. The first pertains to the ways researchers, providers, and others can unintentionally affect the outcomes of their research. P. Jensen, et al., discuss this issue in a recent article about research problems within the evidence-based practices movement: “In the rising quest for evidence-based interventions, recent research often does not give adequate attention to nonspecific therapeutic factors, including the effects of attention, positive regard, and therapeutic alliance.”¹⁷ For example, researchers might have an effect on the process if their individual perspectives or goals bias the way they

¹⁵ Espiritu, R. (2003). What about Promotoras, Shamans and Kru Khmers?: The need to expand the evidence base for diverse communities. *Data Matters* 6: 2, 20. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

¹⁶ The description of internal validity is largely based on information from the following source: Trochim, W. Internal validity. (2002). In *Research Methods Knowledge Base*.
<<http://www.socialresearchmethods.net/kb/external.htm>>.

¹⁷ Jensen, P., et al. (2005). What is the evidence for evidence-based treatments? A hard look at our soft underbelly. Springer Science+Business Media B. V., 7.

approach their work. Providers might decrease the internal validity of the research if, for instance, they try especially hard to help the control group, because they want to compensate for the fact that these families and children may not be receiving the best possible care.

The second concern relates to comparing experimental and control groups. The control element

In this alternative model, particular ethical standards are a more important consideration than the statistical power of a research project.

of research design allows the treatment under study to be assessed as the cause of an intended outcome. Individuals' mental health can be affected by any number of factors, including such things as a change in the season or simply the passage of time. If individuals with a particular diagnosis are randomly assigned to either a group that will be given the treatment being studied or a group that will not be given the treatment, the two groups can be compared to see if the individuals who were given the treatment improve *comparatively more* than those who were not.

Denying children and families in the control group access to [a particular practice] may seem wrong, but there is another way the effectiveness of the practice can be studied.

However, the use of control groups may not be in line with family organization values when providers and/or control group subjects believe that the practice being studied is likely to be effective. Ethical standards of research require that both the family and the provider understand that they are participating in a clinical trial that may randomly deny a treatment that the provider considers effective to a child and family. Refusing to give children and families in the control group access to the practice may seem wrong, especially when there is another way the effectiveness of the practice can be studied. Providers of mental health treatments who are attempting to offer the best possible services to all children and families may be unwilling to give these services to only half of the people involved. In addition, the control group subject and the subject's family may feel anxiety and lack of confidence, since they know they may not be receiving the best possible care. The control group subject and subject's family may also have less confidence in the provider and may not develop a positive relationship with him or her. This anxiety and lack of confidence can have a significantly negative effect on an individual's mental health. In an article about the use of alternative research methodology to study Tibetan medicine, T. Halwes discusses how this kind of uncertainty can "undermine the atmosphere of healing generated by the environment of the clinic and the psychological and spiritual bond between the patient and the physician."¹⁸

Alternatives to research using control groups can be designed to minimize problems with internal validity. Such alternatives can eliminate the control element, as T. Halwes explains, by "comparing the results from patients in the study with historical evidence of what would be expected in people with that particular diagnosis. What percentage of people with that illness would recover, what percentage would continue to suffer the condition chronically.... With each patient [the provider] does the best she can to provide appropriate treatment, and both she and the patient understand that." In this alternative model, particular ethical standards are a more important consideration than the statistical power of a research project. Family organizations recognize the importance of every child and family. The control element of the randomized clinical trial can be a significant barrier to effective care for *all* the children and families involved in clinical studies, including those in control groups, and using a research model that does not include a control element may be a better option for much of the study of practices in children's mental health.

¹⁸ Halwes, T. Research protocols that distort the therapeutic relationship between patient and physician cannot fairly evaluate the effectiveness of traditional medical systems. *Medical Research, Tibetan Style*. <<http://www.dharma-haven.org/tibetan/medicine-research.htm>>.

4. External Validity

External validity¹⁹ refers to the degree to which the conclusions in a study would be true for other people in other settings. It is related to making general conclusions about the research findings. External validity is a central consideration in the evaluation of the evidence base of a practice. For example, if research is conducted only on white subjects, the results can only be fairly assumed to hold true for other white people. When the group of subjects is mixed, including individuals from a variety of ethnicities, races, economic backgrounds, and other areas of difference, the degree of validity is decreased, because differences in outcomes might be attributable to those variables rather than the practice itself. Only when the results of the research are separated out and examined according to the specific area of difference, and when there is a significant number of individuals within that category of difference, can the research be generalized to that subgroup.

External validity is particularly important in relation to cultural competence because of the need to make sure that evidence-based practices are appropriate for children and families from a variety of cultural backgrounds in a variety of settings.

External validity can also be affected by the setting of the research; children's mental health research conducted in a particular setting can only be confidently generalized to similar settings. Research on evidence-based practices that are only studied in a controlled setting has less external validity than that conducted in the actual settings in which the child and family are living. The requirement of achieving a high level of external validity can make the research process more difficult and more expensive. External validity is particularly important in relation to cultural competence because of the need to make sure that evidence-based practices are appropriate for children and families from a variety of cultural backgrounds in a variety of settings. Culturally diverse research is not as well developed as standard research and is more difficult to conduct because external validity requirements can complicate the process, restrict the potential pool of subjects, and be more expensive.

In summary, there are limitations to the standard scientific research model when it is applied to complex circumstances involving children with serious emotional disturbances and their families. Because its primary purpose is to test a particular theory, and the most valued principle involved is control, the randomized controlled trial may not be as suitable as observational methodology to research that is intended to promote discovery. Standard research, which can be an excellent means of evaluating the effectiveness of many established practices, may not lend itself as well as observational research to promoting a continual process of improvement. When family organizations are developing policy positions in relation to the evidence-based practices movement, they may want to consider all the implications of research methodology, including the values they prioritize.

Profile of an Evidence-Based Practice: Multidimensional Treatment Foster Care

Multidimensional Treatment Foster Care (MTFC) was developed from Parent Management Training (PMT). The program is designed to result in increased supervision, positive adult-youth relationships, reduction of destructive peer relationships, and family management skills. It attempts to decrease antisocial behavior, increase appropriate behavior, and build positive social skills, using parents, teachers, and other adults as change agents for the child. Therapists, working with the child and the family, and a program supervisor are involved in the treatment, as the child progresses through a system of supervision, rules, privileges, and rewards.

¹⁹ Trochi
<http://

B. Cultural Competence: How Should Cultural Difference Affect the Study and Utilization of Evidence-Based Practices?

Culture is a critical factor in the study and utilization of evidence-based practices. Issues of universal access to quality and appropriate care, the ability of diverse families to make choices and direct their own care plans, the protection of all children and families' rights to dignity and respect, and the ability of diverse families to engage in research are affected by the ways in which evidence-based practices are articulated, developed, implemented, and evaluated.

Cultural competence in relation to the evidence-based practices movement aims to increase, among the entire range of diverse populations, the access and utilization of children's mental health services, and to ensure that practices are effective and appropriate. Cultural competence also requires increasing the involvement of diverse individuals in the research process, as both researchers and subjects of research. For cultural competence in children's mental health to be achieved, research and the implementation of practices must include actively adding to the knowledge base about culturally diverse groups by focusing specifically on cultural difference, developing new therapeutic approaches based on culture, and publishing and disseminating the results of projects related to cultural difference. In addition, research on practices should take into account the tendency of individuals from culturally diverse groups to distrust the motives of researchers and the systems they represent. Finally, cultural competence involves extending the focus of solutions to problems faced by children and families beyond the children and families themselves. Systemic and social solutions, which address problems in the mental health service system or the larger society, may be more effective and appropriate in many circumstances.

Why Should the Evidence-Based Practices Movement Address Issues of Cultural Competence?

The Supplement to the Surgeon General's Report (2001) describes and documents compelling reasons for making sure that cultural competence issues are addressed in children's mental health treatment, and specifically in the evidence-based practices movement. Below is a summary of those reasons:

- Culture has a strong impact on effectiveness of services;
- Children and families from diverse communities have less access to mental health services;
- Children and families from diverse communities are less likely to utilize mental health services;
- Children and families from diverse cultures are less likely to act as directors of their own mental health service plans;
- Children and families from diverse communities who are in treatment often receive a poorer quality of mental health care;
- Diverse communities are underrepresented in mental health research, both as subjects and as researchers.

to community settings and were not being provided to everyone who came in for care. In 2000 the Office of Minority Health Division of the Department of Health and Human Services (DHHS) issued national standards for culturally and linguistically appropriate services in health care. These standards deal with the need to ensure that all people entering the health care system receive equitable and effective treatment in a culturally and linguistically appropriate manner. They were developed as a means to correct inequities that have existed in the provision of health services and to make those services more responsive to the individual needs of all children and families.

Culturally competent evidence-based practices should include the following components:

- Language access for persons with limited English proficiency;
- Services provided in a manner that does not conflict with diverse cultural beliefs and traditions;
- Providers' awareness of their own cultural orientation, their skills with different cultural groups, and their language capacity;
- Providers' ability to show that they understand diverse children and families' experiences and ways of viewing the world; and
- Providers' awareness and consideration of the effects of institutional racism, prejudice, bias, and stigma on the mental health of diverse children and families.

Family organizations, which represent racially, ethnically, linguistically, and socioeconomically diverse children and families, may want to promote a research process that is as accessible as possible to all children, families, and family organizations.

According to the Surgeon General's Supplement, "Race, ethnicity, culture, language, geographic region, and other social factors affect the perception, availability, utilization, and, potentially, the outcomes of mental health services. Therefore the provision of high-quality, culturally responsive, and language-appropriate mental health services in locations accessible to racial and ethnic minorities is essential to creating a more equitable system."²⁰

Culturally diverse groups have been less likely to utilize mental health services, more likely to drop out of treatment programs, more often misdiagnosed, and more likely to receive poor quality of care. The goal of improving children's mental health services, which is central to the evidence-based practices movement, cannot be achieved for diverse children and families without a deliberate and constant effort to decrease disparities in

access and utilization and increase the cultural competence of services.

2. Access to the Research Process

Some of the problems associated with gaining access to services can be addressed by accelerating the cultural competence research sponsored by federal agencies to develop a scientifically-grounded body of knowledge for improving clinical practices and treatments. Much research on practices and services in children's mental health has not included racially and ethnically diverse individuals. R. Espiritu, in "What About Promotoras, Shamans, and Kru Khmers?" reports, "The evidence base for racial and ethnic minorities is alarmingly incomplete. According to a special analysis performed for the Surgeon General's Report on Mental Health: Culture, Race, and Ethnicity (2001), information on race or ethnicity was not available for nearly half of the 10,000 participants included in clinical trials used to generate treatment guidelines. Furthermore, very few minorities were included in trials reporting data

One of the major complications related to ensuring cultural competence in evidence-based practices concerns the need to study diverse groups separately, to study the effectiveness of existing practices with these groups without adaptations, and to study their effectiveness when adaptations have been made.

on ethnicity and not a single study analyzed the efficacy of the treatment by ethnicity or race.

²⁰ U.S. Department of Health and Human Services. (2001). Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General, Chapter 7. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.

Unfortunately, very little is known about the effectiveness of treatments for ethnic minorities."²¹

The research that has included culturally diverse individuals has not generally identified the outcomes for those individuals so that they can be examined separately. In addition, some research requirements may leave out poor families or single-parent families, who often cannot meet the requirements to participate because they cannot afford to miss work or to pay for child care. Family organizations, which represent racially, ethnically, linguistically, and socioeconomically diverse children and families, may want to promote a research process that is as accessible as possible to all children, families, and family organizations. They may also want to advance a strong understanding within the research community of the cultures of children with serious emotional disturbances and their families, as well as a clear perception of the principles and values of family organizations.

[E]fforts are likely to be most effective when applied in a comprehensive, simultaneous, multilevel, and coordinated fashion.

3. Effectiveness and Appropriateness of Practices and Their Study

There are a number of ways to improve the effectiveness and appropriateness of children's mental health practices and the study of those practices. Along with increasing research on diverse cultural groups, education related to cultural competence also needs to be improved for clinicians and researchers. The use of mandatory cultural competence curricula in clinical training programs and continuing professional education in medicine, social work, and clinical psychology is essential to developing evidence-based practices that are truly culturally competent. Some researchers, providers, and others have suggested that practices should be assumed to be effective for all children, regardless of cultural differences, unless there is evidence that indicates otherwise. Family organizations may want to question this assumption and advocate for any or all of the following: a) increased funding for program development where multicultural practitioners design and develop the practice, b) educational incentives to increase the availability of multicultural researchers and evaluators, and c) the involvement of diverse children and families as research subjects. Multicultural researchers are unlikely to be widely available unless deliberate effort and resources are directed toward all levels of the preparation of qualified individuals who can assume these roles.

One of the major challenges to ensuring cultural competence in the evidence-based practices movement concerns the complexity of multiple factors that affect diverse children and families. Research is only culturally competent when it is conducted in a manner in which both social and cultural processes are examined, so as to minimize superficial cultural analyses. In addition, accounting for the particular characteristics of various systems and policies can complicate the process. A report from the Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*,²² asserts that changes to the system to improve health care delivery for diverse populations should include organizational accommodations that may improve equity, along with policies that reduce administrative and linguistic barriers to care. According to the report, these efforts are likely to be most effective when applied in a comprehensive, simultaneous, multilevel, and coordinated fashion. The report recommends following a well-developed strategic plan that includes the participation of diverse children and families and the communities in which they live, as well as clinicians and administrators.

²¹ Espiritu, R. (2003). What about Promotoras, Shamans and Kru Khmers?: The need to expand the evidence base for diverse communities. *Data Matters* 6: 2, 19. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

²² Unequal treatment: confronting racial and ethnic disparities in healthcare. (2003). A report from the Institute of Medicine. < <http://www.nap.edu/catalog/10260.html>>.

4. Lack of Trust within Diverse Communities

Another reason that culturally competent research is challenging involves the tendency of individuals from some cultural groups to distrust that researchers have the best interest of subjects at heart. Incidents such as the Tuskegee Experiment and the forced sterilization of Native American women, which have taken place in the relatively recent history of mental health care and research, have threatened the confidence of some groups in researchers, medical practitioners, and government agencies. In an article on the Tuskegee Experiment,²³ B. Brunner reports, “For forty years between 1932 and 1972, the U.S. Public Health Service (PHS) conducted an experiment on 399 black men in the late stages of syphilis. These men ... were never told what disease they were suffering from or of its seriousness. Informed that they were being treated for ‘bad blood,’ their doctors had no intention of curing them of syphilis at all. The data for the experiment was to be collected from autopsies of the men, and they were thus deliberately left to degenerate under the ravages of tertiary syphilis—which can include tumors, heart disease, paralysis, blindness, insanity, and death.” President Clinton offered an official government apology for the Tuskegee Syphilis Experiment to the eight remaining survivors on May 16, 1997, but this gesture was too late to affect attitudes of distrust that had developed over time by many members of the communities.

Unlike the Tuskegee experiment, the forced sterilization of many Native American women was not related to research. However, it had a similar impact on the ability of members of these communities to trust health care professionals of all kinds. The online journal, *Native American Political Issues*, explains, “The Native American Woman’s Health Education Resource Center has documented abuses carried out by the Indian Health Services (IHS), Job Corps, and other agencies on which Native American women depend for health care services. ...In 1975 alone, some 25,000 Native American women were permanently sterilized—many after being coerced, misinformed, or threatened. One former IHS nurse reported the use of tubal ligation on ‘uncooperative’ or ‘alcoholic’ women into the 1990s.”²⁴ Beyond the two widely known examples above, many families and communities have had negative experiences involving prejudice and discrimination on a smaller scale, which have also contributed to an attitude of distrust. Family organizations may want to advocate that the mental health service system, in the development, application, and promotion of culturally competent evidence-based practices, should be particularly sensitive to issues of trust in diverse communities.

5. Systemic and Social Solutions Not Related to Practices

A final and crucial consideration about cultural competence and evidence-based practices is connected to their exclusive concentration on children and families as the focus of “solutions.” The movement’s singular emphasis on practices inadvertently implies that individual children and families are the sources of the problems they face, and that the way to solve the problems is to change the people who are experiencing them. Often, however, aspects of the cultural environment, such as poverty, discrimination, and stigma, would be better targets of interventions than children and families. Family organizations may want to encourage a view of difficulties and inadequacies involving children’s mental health services that includes the larger society as a potential source. Indeed, if individual families were asked whether a child’s illness itself or the social consequences of the illness have been more damaging, the answer would, in many cases, be the latter. Evidence-based practices do nothing to lessen social problems, such as the discrimination and stigma often associated with serious emotional disturbances and the poverty that disproportionately afflicts diverse cultural groups.

²³ Brunner
men wit
²⁴ Coerce
<http://>

The movement’s singular emphasis on practices inadvertently implies that individual children and families are the sources of the problems they face, and the way to change the problems is to change the people who are experiencing them.

Often, however, aspects of the cultural environment, such as poverty, discrimination, and stigma, would be better targets of interventions than children and families.

Family organizations may also want to ask whether directing a significant amount of resources toward practices and programs that target a select group of people is the most equitable and efficient strategy. In “The Role of Public Policies in Reducing Mental Health Status Disparities for People of Color,” (2003) M. Alegria, et al., explore how ethnic and racial disparities in mental health result from social factors, such as housing, education, and income. Differences in social factors like these can be addressed, not by practices, but by policies that close economic gaps.²⁵ For example, expansion of the Individuals with Disability Education Act, Section 8 housing vouchers, and the Earned Income Tax Credit have been shown to reduce mental health service inequities. It should be noted that rather than decreasing, the gap in income between the poorest and richest families in America has steadily increased over the past two decades. According to a 2002 press release from the Economic Policy Institute, “Despite the tremendous overall economic growth of the 1980s and 1990s and the low unemployment rates of the late 1990s, the gaps between high-income and low- and middle-income families are historically wide, according to a new study by the Center on Budget and Policy Priorities (CBPP) and the Economic Policy Institute (EPI). ...[P]rior to the late 1970s, economic growth in the United States was more evenly shared.”²⁶ Reversing this disturbing economic trend could be more effective in improving the overall well-being of diverse families than any service system change.

Improving the circumstances of these families requires a holistic ... approach, including system reforms and strategies for advancing the socioeconomic status of America's poorest and most vulnerable families.

Some providers and policymakers are currently suggesting that the bulk of funding directed to serving children with serious emotional disturbances and their families should be allocated to programs that are primarily focused on the delivery of evidence-based practices. G. Gintoli and J. Morris, in “Evidence-based Practices: Essential Elements of Reform, Even in Tough Economic Times,” assert that “there is simply no excuse for spending a nickel on programs that don’t have a high likelihood of success.”²⁷ This remark, which concerns directing South Carolina’s scarce mental health resources toward evidence-based practices, reflects the position that unless an intervention is evidence-based it is unlikely to be successful and should therefore not be funded. Such a position shifts attention away from programs that provide resources rather than treatment to distressed families. The Surgeon General’s supplemental report, “Culture, Race, and Ethnicity,” asserts, “Racial and ethnic minorities in the United States face a social and economic environment of inequality that includes greater exposure to racism and discrimination, violence, and poverty, all of which take a toll on mental health.”²⁸ Improving the circumstances of these families requires a holistic, broad-based, multi-layered approach, including system reforms and strategies for advancing the socioeconomic status of

²⁵ Alegria, M., et al. (2003). The role of public policies in reducing mental health status disparities for people of color. *Health Affairs*, 22 (5): 51-64. <<http://content.healthaffairs.org/cgi/content/abstract/22/5/51>>.

²⁶ Despite past boom times, income gaps have widened in 45 states over the past twenty years. (2002). Press Release. Economic Policy Institute.

²⁷ Gintoli, G., and Morris, J. (2003) Evidence-based practices: essential elements of reform, even in tough economic times. *Data Matters* 6: 2, 25. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

²⁸ U.S. Department of Health and Human Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.

America's most vulnerable families.

In addition, families of all kinds have a number of pressing concerns that are not related to specific treatment options. An exclusive emphasis on evidence-based practices has the potential to direct attention away from those concerns. M. Hurlburt, in "The New Consumers of Evidence-Based Practices," conducted an exploratory study that involved educating families about evidence-based practices and then discussing their responses and concerns. He remarks, "Participants rarely mentioned incorporating EBPs as one of their top priorities, even after reviewing data for these ... interventions. Participants reported having a number of other priorities to which they devoted time. These ... included priorities such as 1) improving the System of Care culture, 2) human resources: improving access for non-English speakers and finding sufficient psychiatry time, 3) setting standards, 4) increasing consumer involvement in service planning, 5) expanding access to services, and 6) decreasing the use of residential treatment services."²⁹

All of these priorities are related to cultural, systemic, and social circumstances, not those of the individual child and family. It is interesting to note that part of the reason families did not prioritize EBPs was that they were not confident the practices would be effective in their individual (more challenging) circumstances, as opposed to those of the research subjects. When mental health programs and services become almost entirely focused on interventions that target individual children, their diagnoses, and their families, issues of stigma and blame are much more likely to surface. In addition, social, economic, and institutional causes, which disproportionately affect diverse children and families, may be ignored.

"Participants [family members] rarely mentioned incorporating EBPs as one of their top priorities, even after reviewing data for these ... interventions."

A succinct yet comprehensive summary of the issues related to cultural competence and the evidence-based practices movement is presented in the "Consensus Statement on Evidence-Based Programs and Cultural Competence"³⁰ (2003) that was disseminated by the National Implementation Research Network. An adapted list of those points follows:

²⁹ Hurlburt, M. The new consumers of evidence-based practices. *Data Matters* 6: 2, 17. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

³⁰ Consensus statement on evidence-based programs and cultural competence. (2003). National Implementation Research Network, the Louis de la Parte Florida Mental Health Institute. <nirn.fmhi.usf.edu/resources/publications/working_paper_2a.pdf>.

Observations About Cultural Competence and Evidence-Based Practices

- We know more about effective practices and programs than what is reflected through research done using randomized controlled trials.
- There is evidence to show that there are programs that are effective with a high degree of certainty for specific problems for specific populations in specific settings. These programs should be supported and available to all children and families.
- Little research related to evidence-based programs has been conducted with diverse populations.
- Where studies have included different racial, ethnic, or cultural groups, small sample sizes have prevented any conclusions regarding the effectiveness of evidence-based programs for these populations.
- In communities where evidence-based programs have been implemented, there is no discernible pattern of success or failure for those that have higher disenfranchisement or poverty levels when compared to other communities that have lower levels.
- Implementation of evidence-based programs depends on the availability of an adequate infrastructure (*e.g.*, financial and human resources, strategies to promote community organization and readiness, implementation and knowledge transfer strategies, fidelity measurement procedures, support from stakeholders). To the extent that infrastructure inadequacies and system failures disproportionately affect people who are poor and who are not white, strategies are needed to address such deficiencies.
- Implementation of evidence-based programs is likely to be facilitated by incorporating systems accountability, quality improvement, and knowledge transfer frameworks. A data-based outcomes orientation is a critical component of these frameworks.
- Currently we do not know whether and what types of adaptations and modifications of an evidence-based program are needed to ensure that its implementation does not create or exacerbate disparities across cultural groups.
- Emerging research suggests that appropriate adjustments can be made for specific cultural groups, and partnerships with representatives of cultural communities can result in more successful implementation.
- Further research is required to understand what adaptations and modifications need to occur to improve the implementation of best practices models in diverse communities. At the same time, support for exploring the development of evidence-based programs targeted to specific cultural communities is needed.
- Roles of children and families from diverse backgrounds should not be limited to being subjects of research. They can participate fully in research and practice design, implementation, and evaluation.
- There is evidence that there are current programs that may actually be harmful, with a disproportionately greater impact on persons belonging to specific racial, ethnic, and cultural groups. Mechanisms for shifting funds from these ineffective and harmful practices to evidence-based and best practice models should be developed and implemented.

C. Family Organization Values: To What Degree is the Evidence-Based Practices Movement Consistent with Family Organization Values?

The values that underlie family organizations can be seen as synonymous with those of cultural competence. However, certain issues related to values are discussed separately here because they form a distinct aspect of the discourse of the children's mental health community. There are ways in which these distinct family organization values have the potential to conflict with aspects of the evidence-based practices movement.

1. Values and the Definition of Evidence-Based Practices

Controversy often develops when various individuals and groups use the same terminology to refer to different subjects. Without a widely accepted definition, a popular word or phrase can lose its initially intended meaning, and begin to spread over a wide area of potential interpretation. Such has been the case with terms like "wraparound" and "advocacy." When terms such as these are used in relation to children's mental health programs and practices, family organizations have a stake in ensuring that their values are reflected in the definitions. In some cases individuals and groups have benefited from coming together to more clearly assess the underlying values of children's mental health terminology and to create clear, collective definitions.³¹

When terms ... are used in relation to children's mental health programs and practices, family organizations have a stake in ensuring that their values are reflected in the definitions.

This issue has arisen in relation to the phrase "evidence-based practices." Its definition differs across and within areas of the children's mental health service system. Most of the differences in definitions have to do with how evidence is defined, categorized, and valued. Systematic and rigorous research and evaluation of various practices has been conducted over the last two decades to determine the degree to which various practices are effective. However, according to K. Hoagwood, "There is currently no consensus on how to define 'evidence-based,' or on when the evidence base, however it is defined, is ready to be deployed."³² A simple description from the Institute of Medicine³³ specifies evidence-based practices according to three key components: "the integration of the best research evidence with clinical expertise and patient values." This definition is somewhat consistent with family organization values in that the "patient" is part of the equation. However, it does not explicitly include families.

³¹ For example, a wide range of groups and individuals connected to the field of children's mental health, including the Federation of Families for Children's Mental Health and the Georgetown University Center for Child and Human Development, came together to define the term "family-driven."

³² Hoagwood, K. (2003). Evidence-based practice in children's mental health services: What do we know? Why aren't we putting it to use?. *Data Matters* 6: 2, 4. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

³³ Institute of Medicine. (2000). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

The following values are of particular importance to family organizations in their definition and conception of evidence-based practices:

- All families from all cultural backgrounds should be able to access and utilize services, and these comprehensive and coordinated services should meet the immediate and anticipated needs of every child and family;
- Programs and services should be family-driven; children and families should be involved in the process of designing, implementing, and evaluating their care plans;
- Services should be strength-based, individually tailored to the unique needs of each child and family, and culturally appropriate.

A definition more suited to the experience of families and family organizations might be inclusive of experiential and observational evidence (for example, “testimonial” evidence of children and families). In addition, family organizations may want to support a definition and conception of evidence-based practices based on criteria that recognize differences among families and groups.

number of agencies and organizations that support children with serious emotional disturbances and their families are beginning to come together to find a definition of “evidence-based practices” that encompasses the perspective and values of families and family organizations. A definition more suited to their experience might be inclusive of observational evidence (for example, “testimonial” evidence of children and families). In addition, family organizations may want to support a definition and conception of evidence-based practices based on criteria that recognize differences among families and groups. H. Ringeisen explains this limitation in “Identifying Efficacious Interventions for Children’s Mental Health,”³⁴ “These criteria [for labeling a practice ‘evidence-based’] set a scientific standard of empirical support. These criteria do not necessarily summarize an intervention’s readiness for broad-scale implementation or an intervention’s applicability for diverse groups.” It is in the best interest of family organizations and the families they represent to come to a better consensus, one that reflects their fundamental values, about what constitutes “evidence” and when a practice can be considered “evidence-based.”

2. Family-Driven, Strength-Based, Individualized Care

Just as definitions of “evidence” and “evidence-based” should encompass the values and concerns of family organizations, the choice and implementation of practices in the care plans of individual children and families should be done in a way that is as consistent as possible with family organization values and principles.³⁵ For families to be able to direct their own care plans effectively, they need to be able to choose from among a comprehensive range of possible practices. There can be no doubt that families desire the availability of the most effective care possible for their children. When existing evidence-based practices are not

³⁴ Ringeisen, H. (2003). Identifying Efficacious Interventions for Children’s Mental Health. *Data Matters* 6: 2, 11. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

³⁵ This issue is addressed in relation to children and families (but not family organizations) in Hoagwood, K. (2003). Evidence-based practice in children’s mental health services: What do we know? Why aren’t we putting it to use?. *Data Matters* 6: 2, 3-5. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development. Hoagwood argues, “[F]rom the outset, research models should incorporate the perspectives of families, providers, and other stakeholders into the design of new treatments, preventive strategies, and services. Only by doing so can issues relating to the relevance of the intervention for stakeholders, the cost effectiveness of the intervention, and the extent to which it reflects the values and traditions of families and community leaders be addressed.”

available to children and families, family organizations may want to advocate for their inclusion within the range of choices for all children's care plans. K. Hoagwood states, "There has been a doubling of research studies on child and adolescent mental health at the National Institute of Mental Health (NIMH) and a tripling of funds for research [over the last decade]. Yet this ... evidence about the impact of mental health interventions has been largely ignored." Hoagwood goes on to remark that families and practitioners are generally unaware of existing evidence-based practices, and that in order for them to be broadly available, the study of practices should be connected to efforts to make practices widely known and accessible.³⁶

In addition, the right of children and families to direct their own care includes their ability to make choices from among existing practices that have not been studied. Hugh Davis, Executive Director of Wisconsin Family Ties, reasons, "With the amount of research that's been done our understanding is growing, which is great. However, in some meetings I've heard it suggested that any initiatives that we fund will have to be evidence-based. I'm concerned that this approach will end up excluding a lot of things that work, but have not yet been deemed an 'evidence-based practice.' These practices could be more effective for some children than an evidence-based practice."³⁷ Family organizations may want to support children and families' options to use existing practices that have not been labeled "evidence-based."

The promotion of the continuous "discovery" of new practices may lead to the development of practices that are more effective for many children and families than existing evidence-based practices.

Along with making existing evidence-based practices available and allowing families to choose from among practices that do not have this label, the process of developing and implementing new practices in areas where evidence-based practices already exist (and the availability of funding for the study of these new practices) should be encouraged. The promotion of the continuous "discovery" of new practices may lead to the development of practices that are more effective for many children and families than existing evidence-based practices.

Addressing the subject of family-driven care, Robert Friedman explains, "The overall vision is of an integrated, accountable, data-based and value-based system for children with mental health needs and their families in which there are available a range of effective services and service providers, in which families can exercise choice of the services they are to receive, and the providers who will offer them, and in which there are continuous efforts at improvement."³⁸ Friedman sets out the following factors in support of this vision:

- Family choice is the right thing to do, it is what each of us wants for our own family, and it is what each family should have;
- There is a developing research base to indicate that providing choice improves the outcomes of interventions;
- There is a growing base of field experience to suggest that family choice creates a more effective, efficient, market-driven, customer-oriented and accountable system than the current system;
- For choice to be meaningful there must be available a range of services and service providers, and information about the effectiveness/ characteristics/ special skills of the

³⁶ Hoagwood, K. (2003). Evidence-based practice in children's mental health services: What do we know? Why aren't we putting it to use?. *Data Matters* 6: 2, 4. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

³⁷ This quotation comes from an informal telephone interview (April 28, 2005) with Hugh Davis, Executive Director, Wisconsin Family Ties.

³⁸ This quotation is taken from a draft outline, "Overall Vision," by Robert Friedman (2005), intended to facilitate the development of a comprehensive overview of issues involved in the movement toward evidence-based practices as it affects family organizations.

services and providers so that a choice can truly be informed.

Families must also be supported in their right to reject practices they do not desire, even when those practices are held to be highly evidence-based. Some evidence-based practices have the potential to interfere with an individual child's sense of dignity or to impair his or her comfort level. For example, Applied Behavior Analysis, which is a therapy intended to help children with autism make eye contact and encourage their speech, among other things, is said by some autistic individuals who have had the therapy to repress their natural form of expression and to border on being abusive. A. Harmon explains, "If an autistic child who screams every time he is taken to the supermarket is trained not to, for example, he may still be experiencing pain from the fluorescent lights and crush of strangers."³⁹ While this practice is very highly regarded by a number of practitioners and many families, it is highly offensive to others. Families should not be pressured by claims involving evidence of effectiveness to adopt practices that do not fit their particular needs and circumstances.

Beyond being a danger to the principle of family-driven care, some aspects of the evidence-based practices movement may have the potential to reverse progress in the direction of strength-based, individualized care. In the process of studying and implementing evidence-based practices, there may be a tendency to focus treatment on diagnoses rather than on individual children. As the families of children with serious emotional disturbances are well aware, children are characterized by far more than their primary diagnoses. Programs incremental efforts add up to less than the sum of their parts. The programs often fall short of providing the right services, in the right way, to the right children at the right time." As the families of children with serious emotional disturbances are well aware, children are characterized by far more than their primary diagnoses.

When children are labeled and treated according to their diagnoses, without "seeing the whole child," not only are treatments less effective, children and families may also feel diminished and stigmatized. Efforts should be made in the implementation and research of evidence-based practices to ensure that children's care plans are formed according to a vision of the whole child and family.

There is also a potential danger, when specific evidence-based practices are institutionalized, that individual children and families for whom they do not work will be blamed for the lack of positive outcomes. This tendency has been broadly witnessed by families of children for whom specific, highly indicated medicines were not effective. In these instances, practitioners have placed more trust in the scientific evidence behind the medication's general effectiveness than in the individual testimony of children and families, insisting that the children are either noncompliant in taking the medication or that they do not have the disorder for which they are diagnosed. According to Pat Solomon, Coordinator of North Carolina Families United, "From the traditional perspective of the service provider professional, when a child doesn't meet the goals the professional has identified and placed in a treatment plan, the child is likely to be viewed as noncompliant with the treatment. This happens all the time in a system-

³⁹ Harmon, A. How about not 'curing' us, some autistics are pleading. (2004, December 20). *New York Times*.

⁴⁰ Little Hoover Commission Report, Young Hearts and Minds, Making a Commitment to Children's Mental Health. (2001). State of California. <<http://www.lh.ca.gov/lhcdir/161/execsumm161.pdf>>.

driven service delivery system as opposed to a child and family-centered service system.”⁴¹ The promotion of family organization values in the evidence-based practices movement may help ensure that progress toward family-driven, strength-based, individualized care is not eroded.

3. System of Care Values and Structure

A final consideration in relation to family organization values and evidence-based practices centers on the values inherent in system of care. Because family organization and system of care values are consistent with each other, family organizations may want to work to ensure that the movement toward evidence-based practices does not undermine system of care structure and values. Some studies have been directed specifically at system of care, and the results, some assert, do not demonstrate its effectiveness in improving clinical outcomes for children. Because system of care is not a practice, it should not be the subject of “effectiveness” studies in the same way that practices are. While system of care can and should be the subject of research, this approach to its study is inappropriate. For example, it would not be appropriate to study whether “shared decision-making” and “respect for differences” are “cost-effective,” or even whether they improve clinical outcomes. Principles such as self-direction and cultural competence are desired outcomes and are basic, unquestioned rights of children and families.

It is both practical and logical to look at system of care as a structure, and to study practices within that context. For example, the goal of a current project of ORC Macro is described as follows: “[T]o examine whether children who receive evidence-based treatment delivered in systems of care experience better outcomes and maintain those outcomes longer than children in the same system who do not receive the evidence-based treatment.”⁴² This study addresses treatment outcomes for children and families who are receiving services within system of care, and it will promote a better understanding of how the “effects of evidence-based interventions can be maximized within systems of care.” Family organizations may want to support a conception of system of care as a structure for the provision of services, including evidence-based practices, that is based on fundamental principles and values that system of care and family organizations share.

Profile of an Evidence-Based Practice: Strengthening Families Program

The “Strengthening Families Program” (SFP) is a family skills training curriculum that is intended to improve outcomes for children, ages 6-12. SFP is a fourteen-week program that includes three separate courses: Parent Training, Children’s Skills Training, and Family Life Skills training, and it has been modified for culturally diverse families. The evidence base of SFP suggests that it reduces problem behaviors in children, improves school performance, and reduces delinquency. It uses strategies such as the provision of transportation, childcare, and family meals to encourage families to stay in the program. The program is intended to be family-centered.

⁴¹ This quotation comes from an informal telephone interview (April 19, 2005) with Pat Solomon, Coordinator of North Carolina Families United.

⁴² This research project is described in detail in Holden, E., et al. (2001). Overview of the national evaluation of the comprehensive community mental health services for children and their families program. *Journal of Emotional and Behavioral Disorders*.

D. Evidence-Based Practices and Policymaking: How Might Family Organizations Influence Government and Service System Mandates Regarding Evidence-Based Practices?

A final general area of concern is policymaking related to evidence-based practices. Family organizations can both influence and be influenced by policymaking. This may be the area in which the evidence-based practices movement can most dramatically affect family organizations' operations and activities.

1. Considerations about Mandates to Include Evidence-Based Practices

As has previously been stated, government involvement in the evidence-based practices movement follows logically on the heels of its promotion of accountability in all publicly funded entities. Many family organizations are well aware of the particular effects of the accountability movement on their organizations, as the Government Performance and Results Act⁴³ requires them to collect data regularly and evaluate the various activities they engage in. The federal government now spends about \$100 billion more annually on services provided by outside sources, including non-profit entities like family organizations, than it does on employee salaries.⁴⁴ According to a recent *New York Times* editorial,⁴⁵

The question now is how the sectors, including nonprofit groups, should be arrayed and managed to produce the best services. ...Holding providers accountable and measuring and tracking their performance has to become a core government responsibility that is as important, if not more so, than managing public employees. Public officials must be careful to retain control of outcomes even while their private partners directly manage services. This requires a delicate balancing act, building in the needed flexibility to enable dynamic change, while not becoming a captive of private vendors.

It might seem obvious that the government, in its role as manager of accountability, should give its all-out support to the development and implementation of practices that have been demonstrated through evidence to be effective. However, there are some vital considerations that should prevent the development of policy and the allocation of funding on that basis alone.

Family organizations, not only as providers of children's mental health services but also as advocates for effective services for the children and families they represent, have a considerable stake in influencing government policy regarding evidence-based practices. A recent report from the national newsletter *Mental Health Weekly*⁴⁶ (2004) discusses how the State of Oregon is requiring its mental health agencies to demonstrate that an incrementally increasing number of their programs are evidence-based:

Beginning July 1, 2005, Oregon's State Office of Mental Health and Addiction Services and four other State agencies will be required to show that at least 25% of its program funding supports evidence-based programs. By July 1, 2007, at least half of the programs funded must be evidence-based and by July 1, 2009 and beyond, 75% of them must be evidence-based. The law adopted last year (SB 267) defines evidence-based programs as one that 1) "incorporates significant and relevant practices based on scientifically-based research" and 2) "is cost-effective." The other State agencies subject to the requirements are the Dept. of Corrections; the Oregon Youth Authority; the State Commission on Children and Families; and the Oregon Criminal Justice Commission.

⁴³ The Government Performance and Results Act (GPRA) of 1993 is legislation that requires accountability in federally funded programs.

⁴⁴ Goldsmith, S., and Eggers, E. (2005, February 21). Government for hire. *The New York Times*.

⁴⁵ Ibid.

⁴⁶ Oregon adopts evidence-based treatment requirement. (2004, May 2). *Mental Health Weekly*.

<<http://www.namisc.org/News/2004/Spring/EvidenceBasedTreatment.htm>>.

The goal is to improve outcomes.

Many individuals have expressed concern that requirements to implement evidence-based practices overlook some important considerations.

Many individuals within the children's mental health service system in Oregon, as well as providers and others nationwide, have expressed concern that requirements to implement evidence-based practices overlook some important considerations. Specifically, there are a number of barriers to their widespread use. One barrier is the unavailability of evidence-based practices that are effective for all children. According to the National Advisory Mental Health Council Workgroup publication, *Blueprint for Change: Research on Child and Adolescent Mental Health* (2001),⁴⁷ "Scientifically proven treatments, services, and other interventions do exist for some conditions but are often not completely effective. In addition, most of the treatments and services that children and adolescents typically receive have not been evaluated to determine their efficacy across developmental periods. Even when clinical trials have included children and adolescents, their treatments have been rarely studied for their effectiveness in the diverse populations and treatment settings that exist in this county. Those interventions that have been adequately tested have not been disseminated to the children and their families who need them, or to the providers who can deliver them."

The existence of evidence-based practices for many diagnoses does not guarantee their effectiveness, appropriateness, or availability to many children. S. Tanenbaum, in "Evidence-Based Practice As Mental Health Policy: Three Controversies and a Caveat," provides an example of the problem of including only specified treatments in policy controlling the availability of services⁴⁸: "The District of Columbia's evidence-based psychotherapy policy permits only dialectical behavioral therapy (DBT) for people with borderline personality disorder (BPD). ...[However, a] compilation of clinical guidelines for BPD concludes that different interventions are most effective for different patients."

Before evidence-based practices can be the required treatment for most children's serious emotional disturbances, they need to exist for the intended outcome areas, be effective for the diverse range of children and families, and be available to all. Currently these conditions are far from being met. As A. Rosenblatt explains, in "Prevalence of Mental Illness among Children and Effectiveness of Services Provided to Them" (2000),⁴⁹ "There are barriers to providing treatments that are proven efficacious to real world clinical settings, including the level of severity of problems faced by youth who receive public mental health services and the level of training, supervision, and time necessary to implement the types of detailed practice protocols that are common in the research environment." These barriers cannot be overcome by mandate. Funding for more extensive research and training must be supplied, and providers must be able to implement effective practices. The Report of the Surgeon General's Conference on Children's Mental Health (2001)⁵⁰ extends this point: "Quality, evidence based treatment is limited to a few narrowly-defined populations or is not available. There is the sense that profitability drives treatment decisions, not model practice." Policy mandates based on a desire for cost-effective treatment may be dangerously simplistic in conception.

Policy should also allow for the need to encourage and prepare providers to offer evidence-based practices. The willingness of providers to become proficient in the implementation of

⁴⁷ The National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment. "Blueprint for Change: Research on Child and Adolescent

Mental Health
⁴⁸ Tanenbaum,
Health Affai

⁴⁹ Rosenblatt,
them. Testimon

Systems change to include an increasing number of evidence-based practice treatments will take a great deal of deliberate effort, a substantial amount of funding, and an enormous amount of time.

eat.

ed to

⁵⁰ U.S./DHHS, Report of the Surgeon General's Conference on Children's Mental Health (2001), 18-21.

these practices and to change their current methods of treatment hinges on providing them

with incentives to do so. These incentives are not currently forthcoming, however, as the Surgeon General's Conference report explains: "Low reimbursement rates and the managed care system make it more difficult for clinicians to take time from their practices for additional training and supervision. There are also too few incentives for busy clinicians to make major changes in their current clinical practice patterns." The barriers to implementation must be strategically and uniformly addressed in order for evidence-based practices to become treatment standards. Family organizations may want to advocate against policy mandates that fail to address the complex array of circumstances necessary for successful implementation.

Systems change to include an increasing number of evidence-based practice treatments will take a great deal of deliberate effort, a substantial amount of funding, and an enormous amount of time. The implementation of the "Nebraska Model," which began in 1995 and is still evolving, is a good example of the extensive time and resources required to integrate evidence-based practices into a service system.⁵¹ Family organizations may want to discourage policy mandates that ignore, not only the limiting factors of time needed for implementation, deliberate effort of providers to develop capacity, and availability of funding for implementation, but a strength-based, family-driven, and culturally competent approach to treatment.

While wariness of policy mandates is warranted in many respects, family organizations may want to support policy that prohibits the use of practices that have been shown to be ineffective or harmful and to support policy that denies funding for the implementation of such practices. For example, in the article, "Panel Finds that Scare Tactics for Violence Prevention are Harmful," (2004),⁵² an NIH panel's examination of studies involving group detention centers, boot camps, and other 'get tough' programs suggests that these programs are ineffective and can be harmful. The results of clinical trials demonstrate that these practices tend to worsen problems of youth violence, in part as a result of grouping young people with behavioral disorders together. The article also addresses research involving the counter-productivity of transferring juveniles to the adult judicial system. In order to advocate effectively against the use of ineffective and/or harmful practices, family organizations may want to make a systematic effort to educate themselves and the families they serve about these practices and the reasons they should not be used.

2. Potential Effects of Policy Mandates on Family Organization Practices

Along with understanding how government policy can affect children's mental health services in general, family organizations should be aware of their potential impact on funding for all practices targeted at children and families. Currently, research on the effectiveness of practices is being funded by various governmental and private agencies, but this funding is

⁵¹ See Ferguson, R., and Baxter, B. (2003). Implementation of an evidence-based intervention in systems of care: the evolution of the Nebraska Model. *Data Matters*: 6, 2, 30. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development. It is particularly important for family organizations to be aware that a large part of the success of this model, according to the article, is the principle that children and families should be approached "with a true belief that they are people of great value and have wonderful resources and strengths."

⁵² See the following article, "Panel Finds that Scare Tactics for Violence Prevention are Harmful," (2004) for a discussion of an NIH panel's examination of group detention centers, boot camps, and other "get tough" programs. <<http://www.omhrc.gov/omhrc/pressreleases/2004press1015.htm>>.

limited. The practices that receive support for research are chosen by policymakers, administrative officials, and select others who are included in the process. A. Slaton recommends looking at the kinds of practices that receive funding and asking: “Whose money paid for the program development and the research—and who will benefit financially from the replication of these practices?”⁵³ Family organizations may want to make a strong effort to take part in the decision-making process to determine where research funding is directed.

Some policy decisions may have the potential to decrease support for the services and supports offered by family organizations. Increasingly, the use of evidence-based practices has become a requirement for maintaining funding of children’s mental health programs. S. Tanenbaum argues, in “Evidence-Based Practice As Mental Health Policy: Three Controversies and a Caveat,” “EBP sets methodological standards that may de-legitimize effective treatments, and when those are incorporated into health policy making, patients and

Policy and funding decisions should not be made without considering the resources, services, and supports that do not fit under the umbrella of evidence-based practices. Otherwise, they may undermine the ability of many child-serving entities, including family organizations, to continue their vital day-to-day operations.

lic] may be adversely affected.”⁵⁴ Policy and funding decisions should not be made without considering the resources, services, and supports that do not fit under the umbrella of evidence-based practices. Otherwise, they may undermine the ability of many child-serving entities, including family organizations, to continue their vital day-to-day operations.

Proponents of family organizations compete for limited financial resources. It is increasingly necessary to be able to document the effectiveness of family organization practices, such as training and individualized assistance, to show as well as possible that they improve outcomes for children and their families. However, demonstrating the effectiveness of many family organization practices through research will take an enormous funding commitment. L. Huang, et al., explains that this is almost certain to be a “formidable task that occurs at a painstakingly slow pace, often requiring ... restructuring programs and allocating an infusion of upfront resources.”⁵⁵

Funding opportunities for such research are available. P. Brounstein reports, “This past year,

⁵³ Slaton, A. (2003). A family perspective on evidence-based practices. *Data Matters* 6: 2, 17. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

⁵⁴ Tanenbaum, S. (2005). Evidence-based practice as mental health policy: three controversies and a caveat. *Health Affairs*: 24, 1. <<http://content.healthaffairs.org/cgi/content/full/24/1/163>>. This article presents a distinctly medical perspective on the controversies involved in the EBP movement. According to the article’s abstract, there are “three distinct but interrelated controversies: how inclusive the mental health evidence base should be; whether mental health practice is a variety of applied science; and when and how the effectiveness goal in mental health is defined.” Tanenbaum continues, “I provide examples of evidence-based policy in mental health. These controversies pertain as well to general medicine. To the extent that they remain unresolved, evidence-based policymaking may lead to ineffective and limited care.”

⁵⁵ Huang, L., Hepburn, K., and Espiritu, R. (2003). To be or not to be evidence based?. *Data Matters*: 6, 2, 1. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development.

CSAP held its first Advancing Science Institute in which programs not meeting the criteria for *Promising* program status were invited to review their intervention and evaluation designs with an eye towards building their evidence base. This activity will be broadened to bring more 'home-grown' programs into the fold of effective evidence-based efforts."⁵⁶ Family organization practices should be considered to be as likely to lead to positive outcomes for children and families as any other providers' practices, and as a result, funding for the research of family organization practices should be equivalent to that of other service providers. Being aware of grants and other opportunities to research their practices is a first step for family organizations in this process.

*Proponents of family organizations compete for limited financial resources.
It is increasingly necessary to be able to document the effectiveness
of family organization practices.*

At the same time, it is not appropriate to try to develop an evidence base involving outcomes for individual children and families for many of the activities of family organizations--such things as legislative advocacy and involvement in service-system decision-making, for example--because these activities are directed toward policy and service system change. To ensure that evidence-based practices policy does not threaten the ability of family organizations to continue to engage in activities like these, family organizations may want to raise the awareness of policymakers that it is neither practical nor logical to extend requirements for demonstrating improved individual outcomes in this direction.

Finally, family organizations may want to ensure that policy and funding decisions involving the research of their practices do not interfere with their ability to direct that research from the first to the final stages. They are in a better position to ensure that the research is faithful to the principles and values of family organizations than independent researchers are. They are also better able to assess the relevance and application of research to the needs and desires of families. The credibility of the leadership role of family organizations in research of their practices may be questioned, and family organizations may want to enhance their ability to provide this leadership through staff training. While the study of family organization practices may require the expertise of formal researchers in some circumstances, supervision of and participation in the process is well within the capabilities of many staff and family members. As with other aspects of children's mental health, research should be family-driven. A. Slaton warns about the potential danger of the absence of families and family organizations in the research/evaluation process by asking, "Will we revert to expert-based decision-making and ignore the progress made toward more democratized development, implementation and evaluation of services for children with mental health issues and their families?"⁵⁷ The principle of family-driven care should extend to the research of family organization practices.

⁵⁶ Brounstein, P. (2003). SAMHSA's national dissemination system for model prevention programs. *Data Matters*: 6, 2, 12. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

⁵⁷ Slaton, A. (2003). A family perspective on evidence-based practices. *Data Matters* 6: 2, 23. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

III. Conclusion: Expanding the Research Base

Expanding the children's mental health research base in several directions has become critical to supporting the values and promoting the success of family organizations. By working to extend the kinds of research methodologies that can be used to establish an evidence base for children's mental health practices, family organizations can promote the cultural competence of the movement and encourage research directed at family organization practices. The focus of evidence-based practice research must be widened to include diverse children and families as subjects, and to promote the training and hiring of multicultural research professionals. By supporting a broader research focus, family organizations can help to make significant inroads toward redressing inequities in the access and use of effective and appropriate mental health services. In addition, family organizations' roles in the evidence-based practice movement should address the necessity for clarity and consensus in definitions of terms, the requirement of consistency with family organization values, and the critical importance of sensible policymaking.

The values of family-driven, strength-based, individualized, and culturally competent care are widely accepted in the mental health community. Currently, however, the evidence-based practices movement has the potential to inadvertently undermine these values, unless family organizations and others carefully monitor the movement's direction.

The family movement has made considerable progress in improving care for children with serious emotional disturbances and their families. The values of family-driven, strength-based, individualized, and culturally competent care are widely accepted in the mental health community. Currently, however, the evidence-based practices movement has the potential to inadvertently undermine these values, unless family organizations and others carefully monitor the movement's direction. By building coalitions with each other, as well as with other children's mental health entities, agency administrators, service providers, and policymakers, family organizations can support a progressive process of researching, developing, and implementing effective and appropriate evidence-based practices, especially in communities that need them the most. This will not happen, however, unless research methodology is suited to the requirements of families and the purposes of family organizations and until issues of cultural competence are comprehensively addressed. Family organizations desire the best possible care for the children and families they serve, and their future roles in the evidence-based practice movement can be a powerful force in achieving that goal.

IV. References

- Alegría, M., et al. (2003). The role of public policies in reducing mental health status disparities for people of color. *Health Affairs*, 22 (5): 51-64. <<http://content.healthaffairs.org/cgi/content/abstract/22/5/51>>.
- Aristotle. *Politics*. Hammondsworth, England: Penguin, 1985.
- Brounstein, P. (2003). SAMHSA's national dissemination system for model prevention programs. *Data Matters*: 6, 2, p.12. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Brunner, B. (2005). The Tuskegee Syphilis Experiment: The U.S. government's 40-year experiment on black men with syphilis. <<http://www.infoplease.com/spot/bhmtuskegee1.html>>.
- Chambless, D., and Ollendick, T. (2001). Empirically supported psychological interventions: Controversies and evidence. *Annual Review of Psychology*, Annual, 2001.
- Chief Seattle. Environmental statement. In *Writing About the World*. Ed. S. McLeod, J. Jarvis, and S. Spear. New York: Thompson, 2005, 695.
- Cobern, W., and C. Loving. (2004). Defining science in a multicultural world: implications for science education. An Interactive Session on Defining Science Within Science Education from Multicultural and Universalist Perspectives. Department of Education, University of Michigan. <<http://www.wmich.edu/slscsp/14.html>>.
- Coerced sterilization of Native American women. (1997). Native American Political Issues. <http://www.geocities.com/capitolhill/9118/mike.html>.
- Consensus statement on evidence-based programs and cultural competence. (2003). National Implementation Research Network, the Louis de la Parte Florida Mental Health Institute. <nirn.fmhi.usf.edu/resources/publications/working_paper_2a.pdf>.
- Despite past boom times, income gaps have widened in 45 states over the past twenty years. (2002). Press Release. Economic Policy Institute.
- Drake, R. E., et al. (2003). Strategies for implementing evidence-based practices in routine mental health settings. *Evidence Based Mental Health*. February 6 (1): 6-7.
- Espiritu, R. (2003). What about Promotoras, Shamans and Kru Khmers?: The need to expand the evidence base for diverse communities. *Data Matters* 6: 2, 20. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Ferguson, R., and Baxter, B. (2003). Implementation of an evidence-based intervention in systems of care: the evolution of the Nebraska Model. *Data Matters*: 6, 2, 30. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Friedman R. (2005). Overall vision. Draft document intended to facilitate the development of a comprehensive overview of issues involved in the movement toward evidence-based practices as it affects family organizations.
- Gintoli, G., and Morris, J. (2003) Evidence-based practices: essential elements of reform, even in tough economic times. *Data Matters* 6: 2, 25. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Goldsmith, S., and Eggers, E. (2005, February 21). Government for hire. *The New York Times*.
- Halwes, T. Research protocols that distort the therapeutic relationship between patient and physician cannot fairly evaluate the effectiveness of traditional medical systems. *Medical Research, Tibetan Style*. <<http://www.dharma-haven.org/tibetan/medicine-research.htm>>.

- Harmon, A. How about not 'curing' us, some autistics are pleading. (2004, December 20). *New York Times*.
- Hoagwood, K. (2003). Evidence-based practice in children's mental health services: What do we know? Why aren't we putting it to use?. *Data Matters* 6: 2, 4. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Holden, E., et al. (2001). Overview of the national evaluation of the comprehensive community mental health services for children and their families program.
- Huang, L., Hepburn, K., and Espiritu, R. (2003). To be or not to be evidence based?. *Data Matters*: 6, 2, 1. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Hurlbert, M. The new consumers of evidence-based practices. *Data Matters* 6: 2, 17. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Institute of Medicine. (2000). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- Jensen, P., et al. (2005). What is the evidence for evidence-based treatments? A hard look at our soft underbelly. Springer Science + Business Media B.V., 7.
- Little Hoover Commission Report, Young Hearts and Minds, Making a Commitment to Children's Mental Health. (2001). State of California. <<http://www.lhc.ca.gov/lhcdir/161/execsumm161.pdf>>.
- National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment. "Blueprint for Change: Research on Child and Adolescent Mental Health." Washington, D.C.: 2001.
- Oregon adopts evidence-based treatment requirement. (2004, May 2). *Mental Health Weekly*. <<http://www.namiscc.org/News/2004/Spring/EvidenceBasedTreatment.htm>>.
- Panel finds that scare tactics for violence prevention are harmful. (2004). A discussion of an NIH panel's examination of group detention centers, boot camps, and other "get tough" programs. <<http://www.omhrc.gov/omhrc/pressreleases/2004press1015.htm>>.
- Ringeisen, H. (2003). Identifying Efficacious Interventions for Children's Mental Health. *Data Matters* 6: 2, 11. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Rosenblatt, Abram. (2000). *Prevalence of mental illness among children and effectiveness of services provided to them*. Testimony before the Little Hoover Commission. <<http://www.lhc.ca.gov/lhc.html>>.
- Slaton, A. (2003). A family perspective on evidence-based practices. *Data Matters* 6: 2, 17. Washington, D. C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
- Tanenbaum, S. (2005). Evidence-based practice as mental health policy: three controversies and a caveat. *Health Affairs*: 24, 1.
- Trochim, W. External validity and internal validity. (2002). In *Research Methods Knowledge Base*. <<http://www.socialresearchmethods.net/kb/external.htm>>.
- Turnbull, A., et al. (1998). Participatory action research as a model for conducting family research. *Journal of the Association for Persons with Severe Handicaps*: 23, 178-188.
- U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.

- U.S. Department of Health and Human Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General, Chapter 7*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.
- U.S./DHHS, Report of the Surgeon General's Conference on Children's Mental Health. (2001). Pp. 18-21.
- Unequal treatment: confronting racial and ethnic disparities in healthcare. (2003). A report from the Institute of Medicine. <<http://www.nap.edu/catalog/10260.html>>.





Family Organization Activities

Statewide Family Networks
Technical Assistance Center

Staff: Shelley Spear Senior Writer/Editor
Chuck Anders..... Writer/Editor, Technical Assistance Coordinator
Gayle Wiler Writer, Technical Assistance Coordinator
Jennifer Clancy Program Director
Roberto Ramos Technical Assistance Coordinator
Sireyia Ratliff.....Executive Assistant

Layout: Sandra McDonaldExecutive Assistant
Sandi BuckExecutive Assistant

This monograph was developed by
United Advocates for Children of California,
Statewide Family Networks Technical Assistance Center.



Table of Contents

I. Introduction.....	1
II. Background	2
A. Brief History of the Family Organization Movement	2
B. Literature Review	5
C. Research Process.....	11
III. Results and Discussion	12
A. Outcomes.....	12
B. Activities.....	13
IV. Conclusion	22
V. References	23
Appendix A – Informant List	26

Abstract: This monograph discusses the intended outcomes and the activities of the family organizations in the Statewide Family Networks program. It is based on data obtained through extensive interviews with leaders from forty-two family organizations. The monograph includes a brief history of the family organization movement, a review of literature related to family organization activities, and a description of the research process. The results of the research are described and discussed in two sections that comprehensively delineate categories of intended outcomes and activities. Examples of activities are included with their descriptions. The monograph concludes with a discussion of potential future steps in furthering the goals of increasing the knowledge base about family organizations and generating an evidence-based framework for family organization programs.

I. Introduction

Family Organization Activities is the fifth in a series of Statewide Family Networks Technical Assistance Center monographs.¹ Based on information about Statewide Family Networks obtained through a comprehensive interview process, the publication reflects the intended outcomes and activities of forty-two Statewide Family Networks. *Family Organization Activities* consists of several components, including the following:

- Background: a brief history of the family organization movement, a literature review related to family organization activities, and a description of the research process.
- Results and Discussion: a delineation of the desired outcomes of Statewide Family Network activities and of the activities themselves, as revealed by interview data. In order to present a clear illustration of the framework of activities, the publication contains specific examples of family organization activities within each category.
- Conclusion: a summary of the findings and a discussion of means for furthering the goals of increasing the knowledge base about and helping to generate an evidence-based framework for family organization activities.
- References and Appendices

The purpose of *Family Organization Activities* is to provide Networks and others with a comprehensive description of the aims and activities that characterize the various organizations. The publication is intended to increase Networks and others' knowledge base about family organizations, their goals, and their activities, as well as to assist in the generation of an evidence-based framework for family organization programs. The data gathered through the interview process may also contribute to the formation of a national model of family organizations. Statewide Family Network leaders and others interested in family organization activities will find this monograph of interest because it provides a uniquely wide-ranging and detailed description of the elements that form family organization programs across the country.

¹ The topic areas that have already been featured are: (1) youth programs, (2) outcome evaluation, (3) cultural competence, and (4) the evidence-based practices movement and family organizations.

II. Background

The purposes of family organizations have been refined over the course of the last several decades as the family movement has grown. During this time family members have gained progressively more central roles in their children's mental health care.

Background information relevant to family organization activities and the research project described here is divided into three sections. The first section narrates a short history of the emergence and development of family organizations. The second section reviews children's mental health literature related to family organization activities. The third is a description of the process involved in the research of family organization activities.

A. Brief History of the Family Organization Movement

The purposes of family organizations have been refined over the course of the last several decades as the family movement² has grown. During this time family members have gained progressively more central roles in their children's mental health care. The evolution of families', and subsequently, family organizations' involvement in children's care has followed a remarkable pattern. In the past the child was viewed as a patient, a passive recipient of professional treatment, and the family had no role beyond observing and supporting the service system. Later, the role of families increased in status as they became participants in the planning and delivery of services for their children. In recent years families have been recognized as full partners in their children's care. Having gained knowledge, skills, and access to influence, families have become strong collaborators and assertive leaders, and they are taking on a wide variety of roles, as advisors, providers, planners, administrators, evaluators, researchers, and advocates, among others. These activities and roles have developed as a part of the function and design of family organizations.

Although the work of grassroots family organizations had been going on for many years, the first documented attempt to organize parents and caregivers into a movement was initiated by the allocation of funding through the Child and Adolescent Service System Program (CASSP), and more specifically, the development of Statewide Family Networks. In 1984 Congress appropriated funds for a new children's mental health initiative, the CASSP program, which was intended to be an overarching mental health system of care for children, adolescents, and their families. The belief that families and surrogate families of children with emotional and behavioral challenges should be full participants in all aspects of the planning and delivery of services became widespread and began to be adopted by public agencies. Family partnership was established as a fundamental part of the CASSP program. A number of state and local family-run organizations, including Statewide Family Networks, emerged or were strengthened through the CASSP program and the subsequent Children's Mental Health Initiative. In the mid-1980s public agencies recognized the importance of providing families with help in navigating the service system so that they could get the best possible services for their children.

A notable element of the family organization movement's history involved the joining together of widely geographically and otherwise diverse organizations. This confluence of family organizations took place in 1988, when a group of caregivers met in Washington, D.C., to establish a steering committee for the planning and creation of a family-run coalition to address the needs of children with emotional and behavioral challenges. The committee ultimately created the Federation of Families for Children's Mental Health, which has been instrumental in

² For a concise description of the family movement, see "Overview of Consumer and Family Movements," in Chapter 2: The Fundamentals of Mental Health and Mental Illness. U.S. Department of Health and Human Services. (1999). Mental Health: A Report of the Surgeon General. Rockville, MD.

supporting and developing family-run organizations across the nation throughout the subsequent history of the movement.

A notable element of the family organization movement's history involved the joining together of widely geographically and otherwise diverse organizations.

Along with supporting the development of new and existing family organizations, the family movement has maintained the fundamental principle that all families and children, including those from a widely diverse range of cultural backgrounds, must receive the services they need, and that those services should be appropriate to individual requirements. In 1989 a document that addressed this value became a foundation for comprehensive systems change. Published by the Georgetown University Child Development Center, "Toward a Culturally Competent System of Care"³ introduced the term "cultural competence" to family organizations. Since their recognition in 1989, the principles and goals involved in cultural competence have been adopted and promoted by family organizations throughout the country.

Whereas the 1980s was a period of development, the 1990s was a decade in which dramatic expansion of the family organization movement took place. Family organization involvement in children's mental health research was a relatively new development at this time and did not significantly extend to the activities of the organizations themselves. Besides being involved in and the subject of specific studies, family organizations were committed to supporting the general conclusions of comprehensive research about the ways in which the system succeeds, and more critical, the ways in which it fails to serve families and children. In 1998 a comprehensive report was published by the National Institute of Mental Health, *Charting the Mental Health Status and Service Needs of Children*.⁴ This report to the National Advisory Mental Health Council made a recommendation for more research that would "attempt to enhance the science side of children's mental health ... [to] serve basic informational needs of the society about the magnitude of the problems faced within the child mental health domain." In response, the United States Department of Health and Human Services sponsored inquiry about children's mental health issues.⁵ Among the reports that resulted from this inquiry were three from the Surgeon General. The Surgeon General's *Mental Health: Report of the Surgeon General (1999)*⁶ asserts that mental illness is a critical public health problem that must be addressed by the nation in a comprehensive way. An outgrowth of this report was the *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda (2001)*,⁷ which supports the following as guiding principles for children's mental health services:

1. Promoting the recognition of mental health as an essential part of child health;
2. Integrating family, child and youth-centered mental health services into all systems that serve children and youth;
3. Engaging families and incorporating the perspectives of children and youth, in the development of all mental healthcare planning; and
4. Developing and enhancing a public-private health infrastructure to support these efforts to the fullest extent possible.

³ Cross, T., Bazron, B., Dennis, K., Isaacs, M. (1989). *Toward a culturally competent system of care*. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

⁴ National Institute of Mental Health. (1998). *Charting the mental health status and service needs of children*. Report from the UNOCCAP Oversight Board to the National Advisory Mental Health Council. Bethesda, Maryland: NAMI. <http://www.nimh.nih.gov/council/archivereports.cfm>.

⁵The inquiry itself is reported in the following publication: The National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment. (2001). *Blueprint for change: Research on child and adolescent mental health*. Washington, D.C.

⁶ U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD.

⁷ U.S. Public Health Service. (2000). *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. Washington, DC: Department of Health and Human Services.

Integrating family-driven services and engaging families in care planning, two fundamental principles of family organizations, were articulated as central to the national agenda. Another report that grew out of the first was [Mental Health: Culture, Race, Ethnicity](#) (2001).⁸ This third document addresses the family organization principle of ensuring the access of all children and families to appropriate and quality services; it addresses the need to pay “special attention to vulnerable, high-need populations in which minorities are over-represented.”

Integrating family-driven services and engaging families in care planning, two fundamental principles of family organizations, were articulated as central to the national agenda.

The twenty-first century promises to be a time of enormous potential for family organization growth and development in relation to new areas of research, as family organizations are turning the focus to their own activities. It is also a time for changes in public policy. One of the most critical mental health policy initiatives of the last few years has been the President’s New Freedom Commission on Mental Health (2003).⁹ The commission has made a number of recommendations that are directly related to the family organization movement, including the following:

- Strengthen early childhood mental health interventions: Implement a national effort to focus on mental health needs of young children and their families that includes screening, assessment, intervention, training, financing of services.
- Consumer/family-driven care: Consumers and families will have the necessary information and the opportunity to exercise choice over the care decisions that affect them.
- Eliminate disparities in mental health care: promote well-being for all people regardless of race, ethnicity, language, place of residence, or age and ensure equity of access, delivery of services, and improvement of outcomes for all communities.

Sandra Spencer, Executive Director of the Federation of Families for Children’s Mental Health, discussed coming together with other children’s mental health advocates to define the term “family-driven”:¹⁰ “It was a great accomplishment for the family movement to begin to achieve the second goal of the President’s New Freedom Commission, which is to ensure that children’s mental health services are consumer- and family-driven. It was important to the national Federation of Families for Children’s Mental Health to play a key role in defining family-driven to mean that family members have a primary role in making all decisions about services, supports, policies, and procedures.”¹¹

[The family movement] has been the source of a steadily amplified family voice to provide support, education, information, and systems change to communities and all the families who live in them.

The family movement has experienced a tremendous amount of progress over the past several decades. Its achievements include increased awareness of the struggles and challenges faced by families, decreased isolation of families who have children with serious emotional disturbances, expanded roles for families in research related to children’s mental health, and revolutionary

⁸ U.S. Department of Health and Human Services. (2001). [Mental Health: Culture, Race, Ethnicity](#). Supplement to Mental Health: Report of the Surgeon General. Rockville, MD: Author.

⁹ New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America*. Executive Summary. Department of Health and Human Services (DHHS) Publication No. SMA-03-3831. Rockville, Maryland: DHHS. <http://www.mentalhealthcommission.gov/>.

¹⁰ The Federation of Families for Children’s Mental Health led the national children’s mental health community in a process of determining a working definition of the term “family-driven care.” That definition can be accessed at the following URL: http://www.ffcmh.org/systems_whatism.htm.

¹¹ This quotation is taken from a personal interview (November 3, 2005).

changes in policy and legislation on local, state, and national levels. The family movement has developed and promoted a strong commitment to the principles of family partnership, children's system of care, cultural competence, and the use of research-based practices in children's mental health. It has been the source of a steadily amplified family voice to provide support, education, information, and systems change to communities and all the families who live in them. Many family organizations are currently celebrating over a decade of success, and some have been in existence considerably longer, as many as twenty years or more. The family organization movement has had a far-reaching and inspiring history that continues to unfold in unanticipated and innovative directions.

B. Literature Review

The literature involving the activities of family organizations that support children with serious emotional disturbances and their families can be divided into three groups that are somewhat, but not entirely sequential. The first wave of literature was focused on promoting partnerships between the individual caregivers of a child and the child's service providers. The second category of literature discussed caregivers as full partners in aspects of the mental health system that extend beyond service delivery, such as policymaking and evaluation of services. The third was focused on family organization activities that are independent of the system.

1. *Partnerships between Parents/Caregivers and Professionals*

Initially, the family and family organization movements concentrated on promoting partnerships between a child's primary caregiver and the child's service provider. Covering four topic areas, the literature on caregiver/provider partnerships presented arguments about the value of partnership, offered practical strategies for family members seeking to establish partnerships with professionals, suggested practical strategies for professionals seeking to establish partnerships with parents and caregivers, and reported on empirical studies of the impact of caregiver/professional partnerships on such things as service satisfaction and child outcomes. It is important to distinguish that the discussion here did not extend to a third party (beyond family members/caregivers themselves), generally referred to as a "parent partner."

Several of the most important initial publications developed a rationale for the practice of partnership. *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services*,¹² (1982) by J. Knitzer, presented an argument in favor of developing services that integrated families as partners in their children's care. In 1986 "A System of Care for Children and Youth with Severe Emotional Disturbances,"¹³ by B. Stroul and R. Friedman, introduced the term "systems of care." The premise of systems of care was that children had needs that cut across various systems, such as mental health, juvenile justice, and child welfare, and that if the system and those who worked in it partnered together and with families, the children would receive better care. *The Skipping Stone: Ripple Effects of Mental Illness on the Family*¹⁴ (1995) called on service providers to hear and address the concerns of all types of family members—children, siblings, grandparents, and other individuals intimately connected with the child's family.

¹² Knitzer, J. (1982). *Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services*. Children's Defense Fund, Washington, D.C.

¹³ Stroul, B. A., & Friedman, R. M. (1986). *A system of care for children and youth with severe emotional disturbances* (Rev. ed.). Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center. A more current description of the system of care model appears in the following source: Stroul, B. A. (1996). *Children's mental health: Creating systems of care in a changing society*. Baltimore: Paul H. Brookes Publishing Co.

¹⁴ Wasow, M. (1995). *The skipping stone: Ripple effects of mental illness on the family*. Palo Alto, CA: Science & Behavior Books Inc.

The premise of systems of care was that children had needs that cut across various systems, such as mental health, juvenile justice, and child welfare, and that if the system and those who worked in it partnered with families, the children would receive better care.

Strategies for family members seeking to establish partnerships with professionals were offered in two seminal publications of the 1980s. A. Hatfield's *Coping with Mental Illness in the Family: A Family Guide*,¹⁵ (1982) a beginner's handbook for families of mentally ill persons, helped to establish a pattern for the inclusion of families in all aspects of the mental health treatment of its members. In addition, the *Consumer Guide to Mental Health Services*¹⁶ (1985), published by the National Alliance for the Mentally Ill, was a fundamental manual for families of mentally ill children. It dealt with choosing a therapist, hospitalization, community services, insurance, long-term planning, and other issues, and urged families to be assertive consumers.

Subsequently, strategies for professionals seeking to establish partnerships with parents and caregivers were the subject of several articles from the 1990s. At this time the focus of the family organization movement shifted from family involvement in treatment to family-driven services. *Families and Mental Illness: New Directions in Professional Practice*¹⁷ (1992) described strategic ways in which professionals and families could work together in developing children's care plans. In "Professional and Provider Perspectives on Family Involvement in Therapeutic Foster Care,"¹⁸ (1999) P. Jivanjee affirmed providers' belief in the value of family involvement as an important part of Therapeutic Foster Care, but pointed to challenges related to providers' lack of training in working with families, as well as the structure of the system. In a companion article, "Parent Perspectives on Family Involvement in Therapeutic Foster Care,"¹⁹ (1999) Jivanjee described caregivers' views about relationships and activities that improved family involvement and that forwarded family goals of developing partnerships in decision-making, decreasing barriers to involvement, and furthering strategies to improve involvement.

At this time the focus of the family organization movement shifted from family involvement in treatment to family-driven services.

A final strand of literature on partnership reported on empirical studies of the impact of caregiver/professional partnerships on such things as service satisfaction and child outcomes. Confronting an entrenched belief among service providers that the system knew what was best for families was the subject of "From Paternalism to Partnership: Family and Professional Collaboration in Children's Mental Health,"²⁰ (1993) by N. DeChillo, et al., which reported on a survey of 455 caregivers of children with severe emotional disorders. The article delineated a number of areas of collaboration between service providers and family members that appeared to lead to more satisfaction, which, in turn, supported better outcomes. Another research project related to the impact of family involvement was presented at the annual conference of the University of South Florida's Research and Training Center for Children's Mental Health; C. Lehman's "Families with Children Who Have Emotional or Behavioral Disorders"²¹ (1996) discussed a study of "the nature and extent of support families received

¹⁵ Hatfield, A. (1982). *Coping with Mental Illness in the Family: A Family Guide*. National Alliance for the Mentally Ill.

¹⁶ National Alliance for the Mentally Ill. (1985). *Consumer guide to mental health services*. Arlington, VA. Updated in 1991.

¹⁷ Marsh, D. T. (1992). *Families and mental illness: New directions in professional practice*. New York: Praeger.

¹⁸ Jivanjee, P. (1999). Professional and Provider perspectives on family involvement in Therapeutic Foster Care. *Journal of Child and Family Studies*, 8(3), 329-341.

¹⁹ Jivanjee, P. (1999). Parent perspectives on family involvement in Therapeutic Foster Care. *Journal of Child and Family Studies*, 8(4), 451-461.

²⁰ DeChillo, N., Koren, P.E., & Schultze, K.H. (1994). From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry*, 64(4).

²¹ Lehman, C.M. Families with children who have emotional or behavioral disorders: An examination of the support families receive and parent perceptions of how helpful these supports are in meeting the needs of their children and families. *A System*

from their informal social networks and from paid professionals, and how helpful these types of assistance were in meeting child and family needs.” The results suggested that services should be coordinated in order to improve outcomes and that parental input should be an important part of decision-making so that services “effectively address child and family needs.” J. Stevenson and D. Srebnik, in “Congruence Between Parent-Professional Ratings of Level of Functioning: Relationships to Collaboration and Satisfaction,”²² (1996) confirmed earlier findings that caregiver satisfaction was tied to caregiver-professional collaboration, while suggesting that caregivers and professionals had differing perceptions of children’s level of functioning, with professionals associating more serious impairment with the child’s family and social environments, and caregivers locating more serious impairment in service system environments. Finally, P. E. Koren, et al, in “Service Coordination in Children’s Mental Health: An Empirical Study From the Caregiver’s Perspective,”²³ (1997) assessed service coordination in relation to family participation, satisfaction with services, comprehensiveness of needs met, and other factors. The study indicated that family participation correlated positively with service coordination, and service coordination with satisfaction.

Overall, literature about the caregiver/professional partnership was concerned with changing the relationship between an individual caregiver and provider in a children’s mental health treatment context. While it was more often discussed as a means of improving outcomes, caregiver involvement was increasingly seen as a right, not a privilege.

2. Parents/Caregivers as Partners in All Aspects of the System

Caregivers were promoted as partners in all aspects of the system to ensure that policies, programs, and services met the needs of families raising children with serious emotional disturbances. Family involvement was increasingly viewed as a strategy to transform the mental health system.

A second category of research and literature examined caregivers as full partners in all aspects of the mental health system, from policymaking to service delivery. The movement toward full involvement followed naturally on the building of caregiver-professional partnerships, and reflected a shift in thinking about the scope of family involvement. Caregivers were promoted as partners in *all* aspects of the system to ensure that policies, programs, and services met the needs of families raising children with serious emotional disturbances. Family involvement was increasingly viewed as a strategy to transform the mental health system. This literature generally focused on the roles caregivers can perform within the system, as evaluators, policymakers, or partners helping other caregivers navigate the system. This category of literature can be divided into three groups. Some of the literature described models for family involvement, while other literature presented different roles parents and caregivers might assume as partners with the mental health system. A third group of literature under this category dealt with empirical research on the impact of family involvement on children’s mental health.

Two important articles addressed plans and models for family involvement. T. Osher’s “Getting Me On Your Team: Building Partnerships with Families”²⁴ (1994) laid out a plan for building relationships between families and all other elements of the children’s mental health service

of Care for Children’s Mental Health: Expanding the Research Base, 9th Annual Conference Proceedings, Research and Training Center for Children’s Mental Health, University of South Florida, Tampa, Florida.

²² Stevenson, J., & Srebnik, D. (1996). Congruence between parent-professional ratings of level of functioning: Relationships to collaboration and satisfaction. A System of Care for Children’s Mental Health: Expanding the Research Base, 9th Annual Conference Proceedings, Research and Training Center for Children’s Mental Health, University of South Florida, Tampa, Florida.

²³ Koren, P.E., et al. (1997). Service coordination in children’s mental health: An empirical study from the caregiver’s perspective. *Journal of Emotional and Behavioral Disorders*, 5(3), 162-172.

²⁴ Osher, Trina W. (1994). *Getting me on your team: Building partnerships with families*. Alexandria, VA: Federation of Families for Children’s Mental Health.

system. In addition, the monograph "Learning From Colleagues: Family/Professional Partnerships: Moving Forward Together,"²⁵ (1998) by J. Adams, et al, concerned issues of power, empowerment, interdependence, mutuality, and reciprocity, and presented a discussion of research and a systems approach to family and professional partnership.

The team recognized the essential nature of family involvement in establishing research questions, designing and implementing evaluations, and analyzing and interpreting data.

The group of literature describing various roles of family members included three notable texts. B. Friesen and B. Huff published an influential article on caregiver-professional collaboration in relation to advocacy; their article, "Parents And Professionals as Advocacy Partners," (1990) made the case for family members and service providers to "work together as advocates on behalf of children and youth with serious emotional, mental, or behavioral disorders."²⁶ With support from the Center for Mental Health Services, the Federation of Families for Children's Mental Health and Macro International collaborated to study family involvement in the evaluation of systems of care. Part of this project, called "the family scan," attempted to form a comprehensive conception of the degree of family involvement and the roles families have performed. The report²⁷ (1999) on the study, which continued through 1998, concluded that family-based organizations take on the roles of collaborators in evaluation projects, advisors of such projects, and advocates for evaluation. The research team for this work included a family member, an evaluator, and an administrator. The team recognized the essential nature of family involvement in establishing research questions, designing and implementing evaluations, and analyzing and interpreting data. S. McCammon, S. Spencer, and B. Friesen, in "Promoting Family Empowerment Through Multiple Roles,"²⁸ (2001) outlined seven roles of families in relation to mental health services for children with serious emotional disturbances: as context; as targets for change and recipients of service; as partners in the treatment process; as service providers; as educators and trainers of professionals, students, and other family members; as advocates and policymakers; and as evaluators and researchers.

A final article in this group examined research on the effects of a particular form of family involvement. P. A. McGrane, et al, in "An Evaluation of the Impact of a Family Partnership Team on a System of Care and the Families It Serves,"²⁹ (1997) reported a preliminary evaluation of a model of family involvement, the "family partnership team," which matched families of children with serious emotional disturbances to family members trained to assist them with their individual needs. The evaluation looked at the impact of the team on families, systems, and cost and use of services.

[H]ow should public agencies be connected to the families and communities they serve?

The category of literature addressing caregivers as partners in all aspects of the system focused on changing how public organizations operate, with the primary change being to involve caregivers in all decisions that affect children who have emotional and behavioral

²⁵Adams, J., et al. (1998). Learning from colleagues: Family/professional partnerships: Moving forward together. Peer Technical Assistance Network. Center for the Study of Social Policy with Council of Chief State School Officers. Federation of Families for Children's Mental Health. National Resource Network for Child and Family Mental Health Services. National Technical Assistance Center for Children's Mental Health.

²⁶ Friesen, B. J., & Huff, B. (1990). Parents and professionals as advocacy partners. Preventing School Failure, 34(3), 31.

²⁷ Center for Mental Health Services. (1999). Annual Report to Congress on the Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program. Atlanta, GA: ORC Macro.

²⁸ McCammon, S., Spencer, S., & Friesen, B. (2001). Promoting family empowerment through multiple roles. Journal of Family Social Work. (5)3.

²⁹ McGrane, P.A. (1997). et al. An evaluation of the impact of a family partnership team on a system of care and the families it serves. A System of Care for Children's Mental Health: Expanding the Research Base, 9th Annual Conference Proceedings, Research and Training Center for Children's Mental Health, University of South Florida, Tampa, Florida.

challenges. These texts posed a fundamental question: how should public agencies be connected to the families and communities they serve?

3. Activities of Family-Run Organizations

The third category of literature about family organizations looked specifically at their activities. This literature reported on descriptions of activities based on empirical data, outlined a framework for understanding how family-run organizations can promote transformation of the children's mental health system, and described research of the impact on children and families of specific family organization activities.

The first group of literature in this category was based on empirical data that described the activities of family organizations. In "Enhancing Family Advocacy Networks: An Analysis of the Roles of Sponsoring Organizations,"³⁰ (1995) H. Briggs and N. Koroloff explained how family participation in system reform efforts increased dramatically between the mid-80s and the mid-90s. Their research and recommendations pertained to evaluation of organizations that sponsored seven early Statewide Family Networks. The authors described the activities/objectives of family organizations according to three categories: supporting families, advocating for system reform efforts, and capacity building of Networks. A second article by Briggs, "Creating Independent Voices: The Emergence of Statewide Family Advocacy Networks," (1996)³¹ studied the (then) twenty-eight Statewide Family Networks' developments and activities, and reported that Networks' accomplishments include "developing useful outreach strategies to ... diverse families, increasing financial resources, furthering infrastructure development, and participating in the design of model system of care policies and legislation." Subsequently, in "The Life Cycle of Family Organizations"³² (1996) Koroloff and Briggs examined the initiation and development over time of the Statewide Family Networks program. In this article the categories of Network activities were expanded to include the following: "(1) mutual support and sharing of information among members; (2) advocacy on behalf of individual families and children; (3) modification and enhancement of the service delivery system; (4) ensuring a family-centered policy agenda through family and professional collaboration." A number of other studies, while not focusing on Statewide Family Networks in particular, looked at activities that Networks and other family organizations employ. A. Klein, et al, in "PIN-FST—Evaluating Satisfaction Through Family Interaction,"³³ (1999) reported on the Parents Involved Network, a family organization devoted to information exchange and influencing service system policy. Their work examined the positive correlation between family involvement and systems change, as suggested by the Family Satisfaction Team survey. A more comprehensive description of family organization activities, which developed out of the above analysis, was set out in the Statewide Family Networks Government Performance and Results Act Report, FY 02-03 (2004), which named ten categories of activities. The categories were training, individual advocacy support, information and referral, support groups, outreach and celebrations, administrative activities and program oversight, evaluation, inform/influence legislators and other policymakers, direct service, and statewide family organization support to local family programs. See the following chart for a description of each of the ten activities.

GPRA Reports for 2001-2005: Descriptions of Ten Activities

1. **Training:** Conducting conferences and workshops, and supporting family members and youth to attend training events. Youth, families and providers may be participants.

³⁰ Briggs, H. E. & Koroloff, N. M. (1995). Enhancing family advocacy networks: An analysis of the roles of sponsoring organizations. *Community Mental Health Journal*, 31(4), 317-333.

³¹ Briggs, H. E. (1996). Creating independent voices: The emergence of statewide family networks. *Journal of Mental Health Administration*, 23(4), 447-457.

³² Koroloff, N. M. & Briggs, H. E. (1996). The life cycle of family advocacy organizations. *Administration in Social Work*, 20(4), 23-42.

³³ Klein, A., et al. (1999). PIN-FST—Evaluating satisfaction through family interaction. 12th Annual Research Conference Proceedings. Research and Training Center for Children's Mental Health, University of South Florida, Tampa, Florida.

2. **Individual Advocacy Support:** One-to-one assistance provided to a family member/youth by a Network staff member. Assistance, support in an IEP or care planning meeting, filing an appeal, and so forth. Distinguished from Direct Services because Individual Advocacy is independent of the youth's service plan whereas Direct Services are part of the service plan.
3. **Information and Referral:** A process, either by phone or in person, to offer family members/youth information about mental health disorders or services and supports provided to family members/youth. Web-based Information: Responses or "hits" to a Network's website. Youth, families, and providers may be recipients.
4. **Support Groups:** Facilitated groups attended by family members/youth for the purpose of offering information or support.
5. **Outreach and Celebrations:** Community events either sponsored by the Network or sponsored by others, in which the Network is a participant. Events may be celebrations, like "Mental Health Month" or education, like a "Service Fair."
6. **Administrative Activities and Program Oversight:** Family members/youth who actively participate in administrative meetings, planning committees or other program oversight activities sponsored by a provider agency.
7. **Evaluation:** Activities completed by the Network to evaluate some aspect of the mental health system including consumer satisfaction or evaluation of the effectiveness of family organization activities.
8. **Inform/Influence Legislators and other Policy Makers:** Participation in efforts to educate or influence an elected official concerning a mental health or related issue.
9. **Direct Service:** One-to-one service or support provided by a staff member of the Network who is part of a treatment team. The direct service or support is part of the youth's service plan.
10. **Statewide Family Organization Support to Local Family Programs:** Activities completed by a staff member of the Network to assist a local family-run organization build capacity to serve local youth/families.

Beyond the literature that described family organization activities, a number of texts established frameworks to suggest how family organizations, independent of the system, could achieve transformation of the system. T. Sosna's three part series of articles on family organizations, "Establishing and Sustaining Family/Professional Partnership in Children's System of Care,"³⁴ (2000) began with "Why Family-Run Programs are Integral to Effective and Efficient Treatment of Children with Serious Emotional Disturbances," which discussed the benefits of collaboration between providers and family organizations. The second, "The Diversity of Family-Run Programs and Organizations," delineated four "points of change" that are targets of family organization activities: the family, direct service staff, agency administrators, and legislators. It also described four "avenues of action": information support and educational activities, formal direct service activities, administrative activities, and individual and legislative advocacy. "The Sustainability of Family-Run Programs" outlined three types of family organizations (grassroots, sponsored, and autonomous) and financial sustainability strategies. Another text promoting family organization activities as a means of transformation was "The Practices and Activities of Statewide and Local Family Organizations: Various Means for Achieving a Common End,"³⁵ (2004) from the Statewide Family Networks Technical Assistance Center.

[O]ne of the central goals of the research project ... is to help establish an evidence base regarding family organization activities.

³⁴ Sosna, T. (2000). Establishing and sustaining family/professional partnerships in children's systems of care. Cathie Wright Technical Assistance Center Updates. (3)1-3.

³⁵ Statewide Family Networks Technical Assistance Center. The practices/activities of statewide and local family organizations: Various means for achieving a common end. (2004). United Advocates for Children of California.

The final topic of literature in this category was empirical research of the impact on children and families of specific family organization activities. The single article on this topic, "Support Groups for Parents of Children with Emotional Disorders: A Comparison of Members and Non-members,"³⁶ (1991) by N. Koroloff and B. Friesen, reported on a survey of parents in and not in support groups. They found involvement with other parents to be the most helpful coping activity for roughly a third of all the parents surveyed. It is appropriate to conclude the literature review with the article above because it represents the direction for research that is most likely to forward one of the central goals of the research project described below, that is, to help establish an evidence base regarding family organization activities.

C. Research Process

The research process detailed below involved three stages. The first stage of conceptualization and planning laid out the project's goals of comprehensively describing the activities of the forty-two Statewide Family Networks and delineating intended outcomes of the activities.

The second stage was comprised of interviewing forty-two Statewide Family Network leaders and transcribing the interviews. The leaders were from the Networks funded in Federal Fiscal Years 2001-02 through 2003-04. The method was a comprehensive interview that included two questions, prefaced by an explanatory statement.

Opening Statement to Interview Subjects:

Family Organization Activities is being created by the Statewide Family Networks Technical Assistance Center for the purpose of providing Networks and others with a comprehensive description of the aims and activities that characterize the various organizations. The publication will facilitate knowledge exchange between Networks and will assist in public relations efforts. It will also help to generate an evidence-based framework for family organization programs.

Interview Questions:

- What are the activities your organization engages in? What else?
- What are the desired outcomes of these activities in relation to their impact on children and families?

The third stage of the project encompassed analysis of data, which involved two separate processes, one for intended outcomes and one for activities.

1. *Data Analysis: Outcomes*

Data analysis regarding the outcomes question was comprised of isolation and categorization of intended outcomes as expressed in informants' responses. Interview transcripts were divided into three groups, with each of three staff members reading and analyzing thirteen transcripts. Discrete outcomes were identified and listed, and the three lists were compiled into one. Two staff members then combined related outcomes into separate groups, and wrote general, labeling outcome statements intended to be inclusive of the connotations of all the statements in that group.

2. *Data Analysis: Activities*

Data analysis regarding the activities question was comprised of identification and categorization of activities discussed in the interviews. "Activity" was defined as "an action

³⁶ Koroloff, N. M., and Friesen, B. J. (1991). Support groups for parents of children with emotional disorders: A comparison of members and non-members. *Community Mental Health Journal*, 27(4).

sponsored by a Network.” Three staff members independently read all the transcripts to isolate the activities each informant described. Staff members recorded the data using, to the degree possible, the actual language of the informant. The three lists of discrete activities were merged into one list, with all duplicates deleted. Two staff members independently reviewed the single list and organized like activities into distinct groups. The two staff members discussed disagreements and reached accord on the final grouping of all activities.

III. Results and Discussion

The following section describes the intended outcomes and activities of family organizations according to the frameworks of categories that emerged from the data analysis.

A. Outcomes

Statewide Family Networks are ultimately working to improve the well-being of children and youth who have mental health conditions and their families. More specifically, Networks are working to ensure that 1) children and youth remain in their communities and at home with their families, 2) succeed in school, both academically and socially, 3) abide by the law and remain out of the juvenile justice system, 4) grow up to be productive, working adults, 5) have social support and are not isolated, 6) have more stable home lives and are less often in crisis, and 7) are healthy, happy and hopeful. To promote these outcomes, Networks work directly with children, youth, and families to change the communities in which they live, and promote transformations to the public systems that provide services to them. This section describes the changes Networks are trying to make to the communities in which children, youth, and families live, as well as the public systems that provide services to them.

The communities in which children and families live impact their well-being. Children and youth who have mental health conditions may be teased in school and their teachers may isolate them due to their mental health condition. Family, friends, and neighbors who do not understand the behavior of children and youth who have mental health conditions may blame the parents and isolate the family. This may lead children to feel less happy and hopeful and lead parents to self-blame, as well.

Networks are endeavoring to 1) increase community members' knowledge, understanding and awareness of children and families, 2) reduce stigma and discrimination against children, youth and families, and 3) build community support and acceptance of children, youth and families.

Statewide Family Networks are working in the community to change how children and youth who have mental health conditions and their families are treated. More specifically, Networks are endeavoring to 1) increase community members' knowledge, understanding and awareness of children and families, 2) reduce stigma and discrimination against children, youth and families, and 3) build community support and acceptance of children, youth and families.

The systems that provide services to children and youth who have mental health conditions and their families also impact their well-being in significant ways. The Networks are actively working to change the system, as well as the services that are provided to children and youth who have mental health conditions and their families, so that the system achieves the following:

- Responds to the needs of individual children and families;
- Provides higher quality care;
- Reflects an understanding of what families and children need;
- Meaningfully involves families at every level of decision making;
- Is culturally competent;

- Reflects the hopes and dreams of parents and caregivers;
- Provides care that is comprehensive and child- and family-centered;
- Funds early identification; and
- Implements system of care.

To promote these changes, the Networks target three different actors, including legislators and other policy makers, service providers, and individual children, youth, and families. Networks work with individual children, youth and families to enhance their knowledge and skills about such issues as accessing services, participating in treatment planning, participating in the policymaking process, managing transition to adulthood, self-advocacy, advocating for others, and working with service providers.

Networks work with service providers to enhance their knowledge and skills. Networks are interested in service providers becoming more knowledgeable about the needs of children and families and evidence-based practices. Networks also work to change the behavior of providers. In particular, Networks are trying to influence providers to help children have better outcomes, to encourage them to more actively partner with parents, and to ensure that they do not blame, shame, or stigmatize children and families.

B. Activities

The analysis of the interview data related to activities yielded twenty-two total categories. The first set of fifteen categories of activities was seen to be directed toward individuals and entities outside the Network itself, while the second set of seven categories of activities was seen to be directed toward organization capacity building, organization strengthening, or organization serving. The first set, referred to as primary activities, was directly focused on achieving the organization's intended outcomes, while the second set, referred to as secondary activities, had an intermediate focus on improving the organization or assisting the individuals connected to the organization in order to achieve the overall mission. These secondary activities, while characteristic of many different kinds of nonprofit organizations, were seen to be of particular importance to family organizations, which may require uniquely tailored training and other support of staff and board members, who are often family members of children with serious emotional disturbances. Other capacity building activities of family organizations were also seen as essential in sustaining their ability to achieve their missions. These activities sometimes connected to distinct aspects of children's mental health (*e.g.*, outreach activities related to national stigma reduction efforts, and chapter development activities related to the particular mental health needs of local communities.)

[C]apacity building activities of family organizations were seen as essential in sustaining their ability to achieve their missions.

Primary Activities

1. Individual Assistance
2. System Services
3. Concrete Needs
4. Support Groups
5. Training Families
6. Youth-Driven Activities
7. Group Information and Referral
8. Conferences

9. Training Professionals
10. Child and Family Teams
11. System Evaluation
12. Administrative Policy
13. Legislative Policy
14. Celebration
15. Public Awareness and Stigma Reduction

Secondary Activities

1. Chapter Development
2. Marketing and Outreach
3. Self Evaluation
4. Board
5. Fundraising
6. Staff Development
7. Staff Morale/Retention/Support

Below is a description of each of the activities, primary and secondary, with examples from the interviews with Statewide Family Network leaders.³⁷ Each description begins with a definition, in italics, that identifies the target of the activity and provides an operational definition of the activity itself.

Primary Activities

1. Individual Assistance

Individual assistance activities are targeted at individual children with serious emotional disturbances and their families. "Individual assistance" refers to the provision of individualized information, referral to services, emotional support, assistance in circumstances of crisis, help accessing services, and assistance in public agency meetings and hearings. A child or family member may receive one of these services or a combination of services over a period of time. These services are provided in-person, by telephone, and through Internet media. Individual assistance in the form of accompanying families to important meetings may serve to ease a family member's discomfort in an unfamiliar situation. Teri Toothman (WV) describes individual assistance as, in part, "attending meetings--IEP meetings, multidisciplinary team meetings, any kind of meeting that a parent might feel uncomfortable going to. We will go with them to it." This kind of individual assistance can also be a means of helping families learn to negotiate the service system. Other types of individual assistance can involve providing mentoring and support for families. Lois Jones (CA) gives an example: "When children are involved with the juvenile court, the parents' obligation is to provide information to the probation officer and the court to let them know what the child needs. We often will go to a hearing with the parent and speak directly to the judge, with the parent's permission, about what the parent wants for their child. In this particular instance, it involved a student who was arrested at school for disruptive behavior. The student had an IEP with mental health services and a behavior plan that had not been reviewed for the past year. We assisted the parent to advocate that the matter be returned to the school district and the IEP process to develop an appropriate program, placement and behavioral interventions that address the disruptive behavior. We also

³⁷ Statewide Family Network leaders are identified by their names and states only. Several of the individuals cited here are no longer in the positions they were in at the time of the interviews, and the job titles of several others have changed in the interim. See Appendix A for a chart that identifies the individuals who were interviewed, their job titles, their states, and the dates of their interviews.

provided the court with copies of the relevant sections of the IDEA as additional support for the parent's position."

Teri Toothman (WV) describes individual assistance as, in part, "attending meetings--IEP meetings, multidisciplinary team meetings, any kind of meeting that a parent might feel uncomfortable going to. We will go with them to it."

2. System Services

System services activities are targeted at children and family members. "System services" refers to the provision of services within a public child-serving system, such as mental health (e.g., contracts with government agencies to do respite services, supervised visitation, case management, etc.). Tressa Eide (MS) outlines a variety of respite services: "We have a planned respite program, and then we do crisis respite. We do group respite. We do all of it. [Planned respite] is what we call Family Time Out. It is up to ten hours a month that a family can get one-on-one respite with a trained, certified provider. Our respite coordinator will interview both the family and, of course, the providers have to go through training, and then they make a match. Generally, the provider and the family work out what they want the provider to do with the child on the day that they do it." Barbara Sample (MT) discusses several other kinds of system services activities: "We have a memorandum of understanding with Maternal Child Health in the Public Health Department for case management services. ...We also contract with a provider organization who do targeted case management, and we ...work both with the child and with the parent. It is one-on-one time with an identified Medicaid-eligible, emotionally disturbed child. It can be anything: we may take them to a movie, we may take them shopping, we may take them to play Ultimate Frisbee. It's ... a form of respite for the parents. ...We also provide for those families whose children have been removed for whatever reason, whether it's because they've been hospitalized or abused and neglected. If for any reason the state or medical facility is recommending supervised visitation, we contract with the state to provide supervised visitation to ensure that children and their parents have as much access to one another as possible."

3. Concrete Needs

Concrete needs activities are targeted at children and families. "Concrete needs" refers to the provision of resources that help to meet the basic needs of children and families, such necessities as food and shelter. When a family lacks the resources to take care of basic needs, Networks have made efforts to assist them. According to Sue Smith (GA), her Network is able to allocate "\$200 a family a year" for food, shelter, utilities, or other immediate needs. Vee Boyd (LA) gives a specific example of how "three families here in Baton Rouge" had no resources for a Christmas celebration: "[W]e provided Christmas for those three families--meals and gifts--it was a complete Christmas."

Vee Boyd (LA) gives a specific example of how "three families here in Baton Rouge" had no resources for a Christmas celebration: "[W]e provided Christmas for those three families--meals and gifts--it was a complete Christmas."

4. Support Groups

Support groups are targeted at individual children and families. "Support groups" refers to activities in a group setting that provide emotional support and information to families. Sarah-Ellen Thompson (AL) outlines the particular structure and function of her organization's support groups: "A couple of board members have local support groups in their towns, [which] tend to be unique to their area. One of them usually has a speaker come in, or they have a video on a different topic. The other one ... doesn't have a designed agenda. They usually happen once a month." Support groups can be more narrowly focused. Carol Gramm (MA) illustrates, "Each

family support specialist runs one or more support groups in their community and/or specialty groups that are topic focused on ... kids [with autism], caregiver self-care, and sibling support." A unique tool for recruiting individuals for support groups was created by Brenda Hamilton (IN), who explains, "We just developed a support group prescription pad [so that] we can get a child-serving entity to prescribe that. Again, my belief is that support groups should be a part of the system of care for those that need it, and it was kind of like a way of saying, 'Hey, you know, this might be appropriate.' It was just a little novelty item where the professional would say, 'Here's the contact names of the support group,' and then on the back have ... the value of what the support group can do for them."

5. Training Families

Training families is targeted at children and families. "Training families" refers to the presentation of information to increase an individual family member's knowledge base or to develop an individual family member's skills. Statewide Family Networks present trainings for children and families on dozens of topics, and may range in scope from hour-long presentations to weekly or even monthly sessions. Jane Walker (MD) illustrates, "We have a family leadership institute.... [F]amilies have to apply for and are accepted to a six-month, one-weekend a month, in-depth training, and that is to become advocates within the system." In addition, training may focus on preparing individuals to become trainers themselves. Connie Nelson (TN) explains, "We have developed a parent-to-parent advocacy training module, so we are now training parents across the state to be advocates and to assist other parents." Some training is intended to support legislative advocacy efforts, as Beverly Baker (ME) comments: "Across all regions we've done training in things like legislative process, voting, joining boards and committees. All of these things are ... geared toward getting families and people with disabilities themselves more actively involved in what's going on in their communities and state and local government."

"We have a family leadership institute.... [F]amilies have to apply for and are accepted to a six-month, one-weekend a month, in-depth training, and that is to become advocates within the system."

6. Youth-Driven Activities

Youth-driven activities are targeted at children, youth, service providers, legislators, and members of the community. "Youth-driven activities" refers to all activities that children and youth direct or have a role in directing. Pat Solomon describes some of the things the youth program does in North Carolina: "Youth have meetings regularly and they have conference calls. They probably meet five times a year. [Conference calls are] almost every month. ...[The youth] are going to be doing a reception to invite some of the leaders of the state and meeting them. ...We have a new division director here, so we're going to be doing a 'meet and greet' with him. The youth program is also a pilot site for C-pass, a consumer support services seventeen-month grant. The youth will be trying to do some training with them. ...A part of our group just had a youth rally. We did plays and we had a fishing booth, and the youth did face painting ... and stuff like that." Jeanne Schulz (OR) discusses youth activities that are both recreational and service-oriented: "The youth program's activities include lots of community fun activities and service projects. Some of their service projects have been helping direct traffic at a community festival [and] packing food boxes at Christmas-time for families through a church-sponsored program that brought the food." About the youth program in Hawaii, Vicky Followell remarks, "Our youth program has several activities. One is learning about the practice of meetings and facilitation. The other activities are doing surveys in the community and asking kids how their treatment has or how have their experiences either helped or not helped them. Our youth have had experiences in the system. There have been things that they say could improve, so they want to help put that information into our system so that people who are providing these services know that this is information that they can utilize

to make their program better. They're invited to speak at different places. The school of social work and school of special education have asked our kids to come and speak to some of their classes. Our kids have sat on different panels and talked about their personal experiences. They [also] did a video ... on their personal experiences."

"The youth program's activities include lots of community fun activities and service projects. Some of their service projects have been helping direct traffic at a community festival [and] packing food boxes at Christmas-time for families through a church-sponsored program that brought the food."

7. Group Information and Referral

Group information and referral is targeted at any combination of groups of children and families, community groups, groups of service providers, and groups of legislators. "Group information and referral" refers to the provision of information related to children with serious emotional disturbances and their families through Internet media, libraries, videotapes, audiotapes, and print publications, such as handbooks and newsletters, as well as information intended to connect individuals with information, services, and support. Individuals independently determine which resources may meet their individual needs. Increasingly, Networks are providing information through the Internet: Lori Reynolds (IA) confirms, "We host and maintain a wonderful website. ... Our logic model Pathways to the Future will be on it within the next couple of days. We have a library of downloadable information. We have many links and resources. Our vision and our mission are on our website. We have a place where families and others can join the federation. We have a place where donations can be given. Principles of family support are on our website. All of our newsletters are also on our website." Sometimes the same information is presented in different mediums. Frances Purdy (AK) outlines examples of group information that appear on the Internet and as print publications: "We've developed material that basically asks questions that parents would ask, and then answers them. ...We've just uploaded questions about bipolar [disorder]. We're currently finishing a book specifically about what you need to ask when your kid is being sent outside the State of Alaska for treatment." Referrals may be made to types of services, as with one named by Diane Flashnick (SC): "We've got a list of parent support groups and contact names and numbers are on [the website]." Morgan Meltz (CT) explains how group referrals can be made according to cities: "[Our website] has crisis services where you can click on the first letter of your town, and [then] click on the name of your town, and you get the contact information for emergency mobile psychiatric services, the different systems of care in the state and their contact information, [and] family advocates." Similarly, Carol Cecil (KY) provides referrals by regions of the state: "We have regional resources, and you can click on your region of the state and it will bring up the mental health center. It will bring up their regional interagency council or their local interagency council, so [contact information is available for] the people who work on that."

8. Conferences

Conferences are targeted at any combination of groups of children and families, community groups, groups of service providers, and groups of legislators. "Conferences" refers to hosting large-scale events that include a variety of activities intended to improve the well-being of children with emotional disturbances and their families. Conferences typically offer a number of workshops and plenary sessions, and may include activities for children and youth. Conferences may be hosted by Networks alone or Networks in conjunction with other organizations. Kathy Wright (NJ) reports on a conference presented by her Network alone: "[W]e do ... our statewide family conference. It's used to educate families and youth to promote public awareness of children's mental health, to reduce stigma that's associated with mental illness, and to promote the ... development and implementation of effective family and professional partnerships." Peggy Nikkel (WY) describes a collaborative conference:

"We're the lead agency for a children's mental health conference ... every year on improving educational outcomes for students with disabilities."

9. Training Professionals

Training professionals is targeted at representatives from organizations, service providers, policymakers, and community members. "Training professionals" refers to the presentation of information to increase an individual's knowledge base or to develop an individual's skills. Oftentimes, family organization training of professionals fulfills in-service or other continuing education requirements. In many cases, however, professionals seek training for its own sake. Jane Adams (KS) provides a specific example of one kind of training: "One of the key activities that we do is wraparound training for providers, so that providers offer quality services and are trained in new wraparound fidelity measures and instruments." Trainings may be done by staff or other individuals associated with the Network. Pat Solomon (NC) mentions training of professionals done by youth: "We engage in ... professional training. The youth are ... training the different agencies and community partners in system of care in working with youth." In some cases, family organization trainers partner with trainers from outside the organization. Lisa Conlan (VT) describes her organization's collaborative training projects: "Those training opportunities have brought in all our interagency partners, and they have all done full-day training. We did the intensive 'It's a Great IDEA' training that the national Federation partnered with PACER Center around."

"One of the key activities that we do is wraparound training for providers, so that providers offer quality services and are trained in new wraparound fidelity measures and instruments."

10. Child and Family Teams

Child and family teams activities are targeted at direct service and administrative staff. "Child and family teams" refers to a family member's ongoing membership in a group, such as a placement review committee or a wraparound team, that makes decisions about the services an individual child and family receives. Sarah Ellen Thompson (AL) describes a "multi-needs" child and family team: "We attend a local meeting called 'multi-needs care.' If a child needs services from two or more public agencies, they may be adjudicated a 'multi-needs child,' and five core agencies, plus other representatives, sit on a local multi-needs team in every county in the state." Lori Cerar (UT) comments that her Network is "part of a rapid response team to find local placements for children coming out of state hospital." Jane Walker (MD) describes a residential treatment center that has "a contract with us, and we have a family member who ... works at the RTC, is employed by us, and is on their management team. [She] is involved in hiring activities, in training activities, in all kinds of ways. She, with the support of their administration, is infusing family involvement."

Lori Cerar (UT) comments that her Network is "part of a rapid response team to find local placements for children coming out of state hospital."

11. System Evaluation

System evaluation is targeted at the service delivery system. "System evaluation" refers to the collection and/or analysis of information to assess the performance, quality, and/or outcomes of system programs and services (e.g., administering questionnaires to assess the quality or outcome of a wraparound program or participating in a quality improvement team to assess a program's compliance with family involvement requirements). Jane Walker (MD) describes evaluation of a state program: "We also had a contract to evaluate respite care services for the state and to develop a protocol for that. ... [T]he respite care providers were sending us the

names, with approval of the families obviously, and then we would contact the families. [We] did, ...over a two-year period, follow-up with the families receiving respite care to be able to determine what the benefits were.” Tressa Eide (MS) tells about working with a specific evaluator: “We do wraparound consultations for the new system of care focus, ...and some of our families are ... interviewers for the system of care grant. They receive training on how to do the interviews for MACRO International.”

12. Administrative Policy

Administrative policy activities are targeted at service system policymakers. “Administrative Policy” refers to activities that are intended to inform and educate service-system policymakers, such as in-person meetings with service system policymakers, membership on service system policy committees, and attendance at service system policy-related meetings. Linda Liebendorfer (NE) gives an example of an administrative policy activity: “We [meet] with the behavioral health regions (there are 6 of them) to work on what we call a systems change contract. We are part of the directors’ meetings, the statewide meetings, and anything that has to do with the program.” Another specific administrative policy activity is described by Cathy Ciano (RI): “We participate in a state level policy group that works for the children’s behavioral health division of DCYF, called Youth, Parent, and DCYF Partnership. The Partnership is hosting a policy summit soon.”

13. Legislative Policy

Legislative policy activities are targeted at legislators and other individuals involved in government policymaking. “Legislative policy” refers to activities that are intended to inform and educate government policymakers about issues involving children with serious emotional disturbances and their families, such as in-person meetings with legislators, in-person gatherings (e.g., rallies), the distribution of letters, the distribution of information through Internet media (e.g., action alerts), drafting of government policy, voter registration drives, membership on government policymaking committees, and attendance at government policy-related meetings. The Utah Network engages in a number of legislative policy efforts, as Lori Cerar reports, “[We do] listserv distribution of legislative advocacy alerts. ... We’re involved with the legislative coalition for people with disabilities in the mental health subcommittee to affect policy at that level. We have a family member who follows all of the issues pertaining to children’s mental health at the legislature, ... [and] a telephone tree.” Hugh Davis (WI) describes some similar strategies: “[We send] emails and alerts distributed to families. ... We continue to advocate for increasing those kinds of programs in a variety of different policies and legislation that would positively impact families.”

“[We send] emails and alerts distributed to families. ... We continue to advocate for increasing those kinds of programs in a variety of different policies and legislation that would positively impact families.”

14. Celebration

Celebration activities are targeted at children, families, service providers, legislators, community members, and/or staff members. “Celebration” refers to the provision of recreational opportunities that contribute to feelings of happiness and satisfaction (e.g., Christmas parties). An elaborate celebration event is depicted by Jane Adams (KS): “We do an annual ‘Oscars’ event. Families every year nominate, through a several month process, people who have done extraordinary things for their family, and the categories are teacher, and case manager, and therapist, and siblings. ... We have a team who have been past years’ winners in that category interview those people to make sure that is the person that they’d most want to represent their field. We give these hand crafted statuettes (little children with their hands raised in the air) to celebrate their contribution to children’s mental health and to thank them at our annual awards ceremony.” Events may incorporate regional or other

cultural traditions of celebration, as in the case of Donna Dittrich's organization in Missouri, which had "an Ozark hoedown with clackers."

15. Public Awareness and Stigma Reduction

Public awareness and stigma reduction activities are targeted at the general public. "Public awareness and stigma reduction" refers to activities that increase knowledge, improve understanding, and decrease stigma related to children's serious emotional disturbances (e.g., Mental Health Month). Karen Taycher (NV) describes some public awareness activities, such as "participat[ing] in community-wide fairs, and television and newspaper interviews, to increase the awareness of children's mental health issues." Youth programs are often involved in public awareness activities. According to Carol Cecil, Kentucky's youth program achieves public awareness through the use of a presentation and video: "[T]he statewide youth council works toward reducing the stigma by educating the public. They do that by doing their presentation called 'The Other Side.' They are currently making a video of that presentation that we're hoping ... to send out to universities, to their social work programs, their special education programs, counseling, [and] psychology, to use as an educational tool for them as they're preparing to go into that field."

Secondary Activities

1. Marketing and Outreach

Marketing and outreach activities are targeted at the general public, specific communities, service providers, and legislators. "Marketing and outreach" refers to the publication and dissemination of information about Networks and their services through Internet media, direct mailings, brochures, and other print publications, as part of fundraising activities, as part of poster and table presentations at conferences, or through in-person mass distribution of materials. Tressa Eide (MS) describes table presentations and other outreach activities: "We're on our children's task force. We did the big picnic, which was Mental Health Awareness Day, out at a park. We try to do an annual awards banquet, and the press come for that usually. And we have a legislator award—those kinds of activities. We put up our banner and our table every place we can think of." Diane Flashnick (SC) uses the Internet to market the Network: "We also have a website. We put information about our organization and a little bit about the national organization." Brooke Schewe (NY) describes using the website to market chapters: "The website has ... information about our chapters and how to become a chapter, [as well as] contact information for our current chapters."

"We put up our banner and our table every place we can think of."

2. Fundraising

Fundraising is targeted at individuals within the community, community organizations, private foundations, and government agencies. "Fundraising" refers to activities that increase a Network's revenue (e.g., grant writing and donor development). Patti Derr (TX) describes a fundraising activity designed to appeal to a large regional audience: "We hold an annual fundraiser, a huge one. It's called the Guadapalooza. This year...[w]e have fifty-one recording artists, but we have three of them that you can see on Country Music Television. ...So we're gearing up for our big, big Texas music splash."

3. Chapter Development

Chapter development is targeted at family organizations within the Network's state. "Chapter development" refers to activities that support the initiation, growth, and improvement of family

organizations (e.g., provision of office machines). Renelle Nelson (MN) lists a broad spectrum of chapter development strategies: "Some of the things that we've done include developing and implementing a kind of strategic planning and divisional technical systems plan. We did interviews, surveys, and held family meetings--small group meetings, because we really wanted to make sure that all diversities would be represented. We also organized and facilitated one small group, a strategic planning discussion to meet technical systems needs that were identified in the survey data. And then again, we provided ongoing technical assistance to them. ...We're fostering the leadership and business management skills of family-controlled groups, networks, and organizations. ...We asked them to fill out an individual technical assistance plan. Some of [the groups to whom we gave computers] needed help to set up an e-mail account. Some of them needed help in accessing and using the Internet. Some of them just wanted information on how to facilitate a workshop in their area." Jane Walker (MD) talks about using focus groups to assist family organizations: "We did two [focus] groups in the last two weeks out in one community in western Maryland. They wanted to start a family organization and wondered how they should go about doing one. I said, 'Well, before you do anything, you need to listen to the families.' So we went out and met with about twenty-five families, just listening to them."

4. Board

Board activities are targeted at Network boards of directors. "Board" refers to activities that improve the functioning of the board of directors (e.g., training). One activity, as Jane Adams (KS) points out, is "extensive training for the board." Sarah Ellen Thompson (AL) describes "board activities" as focused on being a "liaison with other organizations like NAMI, PTA, PTI, and child serving agencies, grant funding search, grant review committee, fundraising, and public awareness events."

Sarah Ellen Thompson (AL) describes "board activities" as focused on being a "liaison with other organizations like NAMI, PTA, PTI, and child serving agencies, grant funding search, grant review committee, fundraising and public awareness events."

5. Self Evaluation

Self evaluation is targeted at individual Networks. "Self evaluation" refers to the collection and analysis of information to assess the performance, quality, and/or outcomes of a Network's programs and services. Peggy Nikkel (WY) addresses the topic of self-evaluation: "We have a client database that's behind a firewall and is HIPAA compliant and that we enter all our client information in. It gathers all the demographics about socioeconomics, actually about their case, about the disorder, the action plan, the progress--we're able to track all the contacts we make with them to report on that. We can know numbers by age, by ethnicity, by location in the state, all that sort of thing. ...[A]n example [from] a little over a year ago: we were receiving from the Department of Family Services only \$10,000 for our family outreach program. I was able to show the percentage of families, three quarters of them, who are being served by [that] agency. Then we went from \$10,000 to three-quarters of a million for our program." Conni Wells talks about one of Florida's many self-evaluation activities: "We're doing organizational report cards. How satisfied are families with the services that they get from us?"

6. Staff Development

Staff development is targeted at Network staff members, including volunteers. "Staff development" refers to activities that increase the knowledge base or develop the skills of staff members (e.g., training). Barbara Sample (MT) describes staff development in her Network: "Every week we have a staff meeting that's an hour and a half long. One hour is devoted to training and a half hour is devoted to business. ...We [also] send staff to conferences." Malisa Pearson (MI) explains that her organization does "six to eight trainings for our staff each year,

formal skill development for our actual paid advocates, but we will also identify parents throughout the year that have an interest in becoming more skilled and knowledgeable in the advocacy arena. ... [We also] provide two-day trainings in the statewide office for staff and parents."

7. Staff Morale/Retention/Support

"Some of our staff members are actually clients. They work with another family outreach specialist for their child and take them as their advocate to meetings and things. I obviously have administrative discretion around this. If there's illness or very unique situations that might come up for a staff member, we really do try to support them and do strength-based work."

Staff morale/retention/support is targeted at Network staff members, including volunteers. "Staff morale/retention/support" refers to activities that improve the confidence, emotional health, and motivation of staff members (e.g., provision of bonuses). Peggy Nikkel (WY) discusses staff support involving parenting children with serious emotional disturbances: "Some of our staff members are actually clients. They work with another family outreach specialist for their child and take them as their advocate to meetings and things. I obviously have administrative discretion around this. If there's illness or very unique situations that might come up for a staff member, we really do try to support them and do strength-based work." Sue Smith (GA) explains some strategies for maintaining staff morale: "We have an active play program. ...We have aerobics three times a week. We have a spring fling, fall fling, an employee appreciation day/banquet, and employee of the month. ...Stuff to try and keep people going, because this is hard work."

As the above descriptions make clear, family organizations across the country implement a broad continuum of primary and secondary activities. All of the primary activities are intended, in and of themselves, to achieve positive outcomes for children and their families. At the same time, activities differ in the means by which they are meant to induce change. Rather than one activity resulting in a single outcome, the activities often work together to achieve a series of smaller impacts that may combine to effect substantial change. To perform their activities, family organizations need to have strong infrastructure, financial and other support, and sufficient staff with appropriate knowledge and skills. The secondary activities of Networks can be enormously important in ensuring that they are able to achieve their aims.

IV. Conclusion

With the knowledge it has generated, this research project can improve family organizations' understanding of each other and the understanding of family organizations by others within and outside of the children's mental health system. Increased awareness of the intended outcomes of family organization activities can help individuals, organizations, and others with collaboration efforts, as they discover common objectives. Expanding the knowledge base regarding organizations' activities can increase the public's grasp of the enormous role that family organizations can play and are playing in transforming the children's mental health system and improving the lives of children and their families.

[B]y initiating a process of delineating and standardizing activities, the monograph can assist in laying the groundwork for the development of an evidence base for family organization activities. As family organizations discover their shared interests, they are better able to find ways to combine their efforts and resources to research and evaluate the effectiveness of what they do, and ultimately, to increase their effectiveness.

In addition, by initiating a process of delineating and standardizing activities, the monograph can assist in laying the groundwork for the development of an evidence base for family organization activities. As family organizations discover their shared interests, they are better able to find ways to combine their efforts and resources to research and evaluate the effectiveness of what they do, and ultimately, to increase their effectiveness. At the same time, we must all recognize that family organizations and their activities are not static. Their aims and activities continue to change as their roles inside of and outside of the children's mental health system evolve. System transformation is a process that requires flexibility and resilience.

Further research is needed to describe in more detail the program models family organizations are using to implement the various activities described in this monograph. The Statewide Family Networks Technical Assistance Center has moved in this direction with the Youth Program Manual. However, the activities of youth-directed programs comprise an impressive array of opportunities for growth and services to the public; family organizations and their youth programs could benefit from a much more intensive analysis. It is our hope that family organizations and others will step up their research and support for research of a wide range of family organization activities.

References

1. Adams, J., et al. (1998). Learning from colleagues: Family/professional partnerships: Moving forward together. Peer Technical Assistance Network. Center for the Study of Social Policy with Council of Chief State School Officers. Federation of Families for Children's Mental Health. National Resource Network for Child and Family Mental Health Services. National Technical Assistance Center for Children's Mental Health.
2. Briggs, H. E. & Koroloff, N. M. (1995). Enhancing family advocacy networks: An analysis of the roles of sponsoring organizations. *Community Mental Health Journal*, 31(4), 317-333.
3. Briggs, H. E. (1996). Creating independent voices: The emergence of statewide family networks. *Journal of Mental Health Administration*, 23(4), 447-457.
4. Center for Mental Health Services. (1999). Annual Report to Congress on the Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program. Atlanta, GA: ORC Macro.
5. Consumer Guide to Mental Health Services. (1985). Arlington, VA: NAMI. Updated in 1991.
6. Cross, T., Bazron, B., Dennis, K., Isaacs, M. (1989). Toward a culturally competent system of care. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.
7. DeChillo, N., Koren, P.E., & Schultze, K.H. (1994). From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry*, 64(4).
8. Friesen, B. J., & Huff, B. (1990). Parents and professionals as advocacy partners. *Preventing School Failure*, 34(3), 31.
9. Hatfield, A. (1982). Coping with mental illness in the family: A family guide. National Alliance for the Mentally Ill.
10. Jivanjee, P. (1999). Parent perspectives on family involvement in Therapeutic Foster Care. *Journal of Child and Family Studies*, 8(4), 451-461.
11. Jivanjee, P. (1999). Professional and provider perspectives on family involvement in Therapeutic Foster Care. *Journal of Child and Family Studies*, 8(3), 329-341.
12. Klein, A., et al. (1999). PIN-FST—Evaluating satisfaction through family interaction. 12th Annual Research Conference Proceedings. Research and Training Center for Children's Mental Health, University of South Florida, Tampa, Florida.
13. Knitzer, J. (1982). Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services. Children's Defense Fund, Washington, D.C.
14. Koren, P.E., et al. (1997). Service coordination in children's mental health: An empirical study from the caregiver's perspective. *Journal of Emotional and Behavioral Disorders*, 5(3), 162-172.
15. Koroloff, N. M. & Briggs, H. E. (1996). The life cycle of family advocacy organizations. *Administration in Social Work*, 20(4), 23-42.
16. Koroloff, N. M., and Friesen, B. J. (1991). Support groups for parents of children with emotional disorders: A comparison of members and non-members. *Community Mental Health Journal*, 27(4).
17. Marsh, D. T. (1992). Families and mental illness: New directions in professional practice. New York: Praeger.
18. McCammon, S., Spencer, S., & Friesen, B. (2001). Promoting family empowerment through multiple roles. *Journal of Family Social Work*, (5)3.
19. McGrane, P.A., et al. (1997). An evaluation of the impact of a family partnership team on a system of care and the families it serves. A System of Care for Children's Mental Health: Expanding the Research Base, 9th Annual Conference Proceedings, Research and Training Center for Children's Mental Health, University of South Florida, Tampa, Florida.

20. National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment. (2001). *Blueprint for Change: Research on Child and Adolescent Mental Health*. Washington, D.C.
21. National Institute of Mental Health. (1998). *Charting the Mental Health Status and Service Needs of Children*. Report from the UNOCCAP Oversight Board to the National Advisory Mental Health Council. Bethesda, Maryland: NAMI. <http://www.nimh.nih.gov/council/archivereports.cfm>.
22. New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America*. Executive Summary. Department of Health and Human Services (DHHS) Publication No. SMA-03-3831. Rockville, Maryland: DHHS. July 2003. <http://www.mentalhealthcommission.gov/>.
23. Osher, T. W. (1994). *Getting me on your team: Building partnerships with families*. Alexandria, VA: Federation of Families for Children's Mental Health.
24. Sosna, T. (2000). *Establishing and sustaining family/professional partnerships in children's systems of care*. Cathie Wright Technical Assistance Center Updates. (3)1-3.
25. Statewide Family Networks Technical Assistance Center. (2004). *The practices/activities of statewide and local family organizations: Various Means for Achieving a Common End*. United Advocates for Children of California.
26. Stevenson, J., & Srebnink, D. (1996). *Congruence between parent-professional ratings of level of functioning: Relationships to collaboration and satisfaction*. A System of Care for Children's Mental Health: Expanding the Research Base, 9th Annual Conference Proceedings, Research and Training Center for Children's Mental Health, University of South Florida, Tampa, Florida.
27. Stroul, B. A., & Friedman, R. M. (1986). *A system of care for children and youth with severe emotional disturbances* (Rev. ed.). Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center. A more current description of the system of care model appears in the following source: Stroul, B. A. (1996). *Children's mental health: Creating systems of care in a changing society*. Baltimore: Paul H. Brookes Publishing Co.
28. U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD.
29. U.S. Department of Health and Human Services. (2001). [Mental Health: Culture, Race, Ethnicity](#). Supplement to *Mental Health: Report of the Surgeon General*. Rockville, MD.
30. U.S. Department of Health and Human Services. (1999). *Overview of consumer and family movements*. Chapter 2: *The Fundamentals of Mental Health and Mental Illness*. *Mental Health: A Report of the Surgeon General*. Rockville, MD.
31. U.S. Public Health Service. (2000). *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. Washington, DC: Department of Health and Human Services.
32. Wasow, M. (1995). *The skipping stone: Ripple effects of mental illness on the family*. Palo Alto, CA: Science & Behavior Books Inc.

Appendix A

Informant List

Note: The information below identifies individuals and their positions at the time of the interviews.

State	Organization	Network Leader	Date
Alabama	Alabama Family Ties	Sarah Ellen Thompson, Executive Director	4-8-04
Alaska	Alaska Youth and Family Network	Frances Purdy, Executive Director	4-8-04
California	Parents Helping Parents	Lois Jones, Executive Director	6-17-04
Colorado	Federation of Families for Children's Mental Health – Colorado Chapter	Ann Schrader, Executive Director	4-22-04
Connecticut	Families United FCMH, Inc.	Morgan Meltz, Executive Director	4-3-04
Florida	Florida Institute for Family Involvement	Conni Wells, Executive Director	5-18-04
Georgia	Georgia Parent Support Network, Inc.	Sue Smith, Executive Director	5-10-04
Guam	Proceed, Inc	Mildred Lujan	5-20-04
Hawaii	Hawaii Families As Allies	Vicky Followell, Co-Executive Director	5-6-04
Idaho	Idaho Federation of Families for Children's Mental Health, Inc.	Marlyss Meyer, Executive Director	5-11-04
Indiana	Indiana Federation of Families for Children's Mental Health, Inc.	Brenda Hamilton, Executive Director	4-12-04
Iowa	Iowa Federation of Families for Children's Mental Health, Inc.	Lori Reynolds, Executive Director	4-27-04
Kansas	Keys for Networking, Inc.	Jane Adams, Executive Director	5-19-04
Kentucky	Kentucky Partnership for Families and Children, Inc.	Carol Whelan Cecil, Executive Director	4-7-04
Louisiana	Louisiana Federation of Families for Children's Mental Health	Vee Boyd, Executive Director	5-19-04
Maine	Maine Parent Federation	Beverly Baker, Executive Director	6-8-04
Maryland	Maryland Coalition of Families for Children's Mental Health	Jane Walker, Executive Director	5-3-04
Massachusetts	Parent/Professional Advocacy League	Carol Gramm, Project Coordinator	4-27-04
Michigan	Association for Children's Mental Health	Malisa Pearson, Staff Development & Community Education Coordinator	4-13-04
Minnesota	Minnesota Statewide Family Network	Renelle Nelson, Project Coordinator	4-15-04

State	Organization	Network Leader	Date
Mississippi	Mississippi Families As Allies, Inc.	Tressa Eide, Director of Family and Youth Services	5-26-04
Missouri	MO-SPAN	Donna Dittrich, Executive Director	4-21-04
Montana	Family Support Network	Barbara Sample, Executive Director	4-16-04
Nebraska	Nebraska Federation of Families for Children's Mental Health	Linda Liebendorfer, Executive Director	6-27-04
Nevada	Nevada P.E.P. Inc.	Karen Taycher, Executive Director	5-19-04
New Jersey	New Jersey Parents' Caucus, Inc.	Kathy Wright, Executive Director	6-7-04
New Mexico	Parents for Behaviorally Different Children	Delfy Roach, Executive Director	5-4-04
New York	Families Together in New York State	Brooke Schewe, Director of Outreach and Development	5-11-04, 5-14-04
North Carolina	North Carolina Families United	Pat Solomon, Project Coordinator	5-4-04
Oklahoma	Parents As Partners	Janice Garvin, Board Chairperson Melody Andrews, Executive Director	5-19-04 6-9-04
Oregon	Oregon Family Support Network, Inc.	Jeanne Schulz, Interim Executive Director	5-6-04
Rhode Island	Parent Support Network of Rhode Island	Cathy Ciano, Executive Director	5-6-04
South Carolina	Federation of Families for South Carolina	Diane Flashnick, Executive Director	4-30-04
Tennessee	Tennessee Voices for Children	Connie Nelson, Coordinator	6-12-04
Texas	Texas Federation of Families for Children's Mental Health	Patti Derr, Executive Director	4-12-04
Utah	Allies with Families	Lori Cerar, Executive Director	4-20-04
Vermont	Vermont Federation of Families for Children's Mental Health, Inc.	Lisa Conlan, Executive Director	6-15-04
Washington	A Common Voice for Pierce County Parents	Judie Rich, Project Coordinator	5-21-04
Washington, D.C.	Family Advocacy and Support Association, Inc.	Phyllis Morgan, Executive Director	5-3-04
West Virginia	Mountain State Parents, Children and Adolescent Network	Teri Toothman, Executive Director	5-14-04
Wisconsin	Wisconsin Family Ties, Inc.	Hugh Davis, Executive Director	5-3-04
Wyoming	UPLIFT	Peggy Nikkel, Executive Director	4-28-04



United Advocates for
Children of California



Statewide Family Networks
Technical Assistance Center

A project of United Advocates for Children of California