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.

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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. 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 Health (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

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the processes and policymaking regarding their development, research, implementation, and evaluation.

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.” 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

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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.\footnote{The first two of these premises are adapted from those articulated by Huang, L., Hepburn, K., and Espiritu, R. (2003). To be or not to be evidence based?. Data Matters: 6, 2. Washington, D. C.: National Technical Assistance Center for Children’s Mental Health, Georgetown University Center for Child and Human Development. Many of the issues mentioned subsequently are also addressed in the above publication. <www.dhh.state.la.us/offices/publications/ pubs-142/Data%20Matters%20Issue%2006.pdf>.

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

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

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

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.” 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.

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.” 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.

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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.  

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

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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” will

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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.

10 This is a fictitious training label.
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), is currently the most highly valued method in establishing evidence-based practices, 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.

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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 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

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

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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.

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

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practice, rather than other possible factors, can be said to have resulted in an outcome. 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.” For example, researchers might have an effect on the process if their individual perspectives or goals bias the way they 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 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, especially when 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

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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.

4. External Validity

External validity\(^{19}\) 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.

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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.
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.
1. Access to Evidence-Based Practices

In 1999 the Surgeon General reported that evidence-based treatments were not being adapted 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.

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.”

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.

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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 on ethnicity and not a single study analyzed the efficacy of the treatment by ethnicity or race. Unfortunately, very little is known about the effectiveness of treatments for ethnic minorities.”

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.

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

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

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, 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.

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, 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.”

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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.” 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.

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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


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

racism and discrimination, violence, and poverty, all of which take a toll on mental health.”

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 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.”

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.

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” (2003) that was disseminated by the National Implementation Research Network. An adapted list of those points follows:

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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 are 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

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.

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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, are currently involved in a process of defining the term “family-driven.”


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 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

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with family organization values and principles.\textsuperscript{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 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.\textsuperscript{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.”\textsuperscript{37} Family organizations may want to support children and families’ options to use existing practices that have not been labeled “evidence-based.”

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.

\textsuperscript{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.”


\textsuperscript{37} This quotation comes from an informal telephone interview (April 28, 2005) with Hugh Davis, Executive Director, Wisconsin Family Ties.
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.” 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 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.” 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 and families and their unique needs. A section of the report of the Little

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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.

Hoover Commission, called “Seeing the Whole Child,” explains why it is important to approach mental health care from a child and family, rather than a practice-centered perspective: “Over the last 10 years, experts have documented the complex needs of troubled children, and the importance of sophisticated solutions. Despite the integrity of individual 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 on 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-driven service delivery system as opposed to a child and family-centered service system.” 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

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

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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 Act 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. According to a recent *New York Times* editorial:

*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* (2004) discusses how the State of Oregon is beginning to require its mental health agencies to demonstrate that an incrementally increasing number of their programs are evidence-based:

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


45 Ibid.

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. 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.”

It makes sense that 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, hence a citation:


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 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.

evidence-based practices into a service system. 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), 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 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?” Family organizations may want to make a strong effort to take part in the decision-making process to determine where research funding is directed.

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.”


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 the [public] 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.

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 individual advocacy, 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, 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

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\(^{54}\) 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.”


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 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 effectiveness 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.

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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 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


