

CLAIMING CHILDREN



FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH ... SUMMER 1998

Special Theme Issue

Making Family Participation in Research and Evaluation a Priority

Barbara Huff, Executive Director

We have come a long way from when the only association families had with researchers and evaluators was as subjects. I remember encouraging researchers to be respectful of families they were studying and to *show their support by providing them with compensation for their time, offering to pay for child care, and providing transportation to the interview sites.* And while today I still believe just as strongly in these recommendations, we also have shifted our attention to a more fundamental concern—full family participation in research and evaluation.

Full participation requires a rethinking about what family involvement in research and evaluation really means. Let me share with you my perspective.

Are the Research Findings Usable?

For years, family members have lamented that research and evalua-

tion rarely answers or gets at the “real” issues. In too many cases our immediate response after reading a research report is “so what?”—or in other words, “how does this research finding relate to getting help for my child in the real world?” It’s almost as if researchers live in a different world from families. Too often, they choose outcomes for study that family members find meaningless—how many times have we seen evaluators select length of hospital stays or overall school attendance and achievement as key variables, when we might argue that other variables (such as the child attends school regularly and gets good grades, stays in off the streets at night and has dinner with the family) have more validity?

As we think about this dilemma, it becomes very clear to me that the point is not that we disagree, but that family members **need valid and usable research.** Family members need valid research that we can point to when advocating for bet-

(continued on page 2)

INSIDE

- Family Participation in Research and Evaluation—A Priority* **1**
- Family Centered Evaluation Curriculum* **3**
- Why Family Participation Is Important* **5**
- Families as Full Partners* **6**
- Participation in Large Scale Evaluations* **9**
- About Research* **10**
- Families Create Satisfaction Survey* ... **12**
- From the President* **13**
- Capitol Connection* **14**
- Young People’s Voices* .. **15**
- Annual Conference* **16**
- News and Notes* **16**

Al Duchnowski served as the guest consultant to this issue.



Making Family Participation in Research and Evaluation a Priority (continued from page 1)

ter services for our children. Advocacy efforts require that we have evaluation data on programs that shows children do better on real outcomes that matter and have meaning, that families are satisfied, and that the program is cost effective. This is what families mean when they call for usable research.

Ensuring Research is Usable

Because we have the most to gain and lose, participating in research and evaluation must become a priority for family members. We need to be full partners with researchers and evaluators.

I know that full participation will not

come easy. We must help researchers eliminate their fears that our involvement will violate the scientific rigor of their work. We can begin by becoming knowledgeable about the language of research and how evaluations are conducted.

“Nothing about me without me.” Just as providers should not plan family services without including the family, the same principle can be applied to evaluation and research.

In this issue of **Claiming Children** we describe how family members across the country are becoming partners with evaluators and researchers.

Family members should be involved in all research activities, including:

- *Conceptualizing and formulating questions for research.*
- *Designing research and evaluation studies.*
- *Selecting and critiquing assessment instruments.*
- *Gathering, analyzing, and interpreting results.*
- *Drawing conclusions and disseminating findings.*

Ethical Issues that Concern Families

Trina Osher, Policy and Research Coordinator, Federation

Mary Telesford, Training Coordinator, Federation

As families engage in research and evaluation projects, they should feel comfortable raising ethical issues that may arise in the study. Examples include:

- **Children are people first.** The research can acknowledge this by using language that puts the children before the disability or diagnosis. Language used should also be family friendly and jargon free.
- **Children are members of families.** Research must strive for cultural competence and demonstrate respect for diversity and the varied experiences of families regardless of how they are configured.
- **Participation in research should never jeopardize a family.** There is no moral or ethical justification for research that puts children and their families at even the most minimal risk. Care must be taken to ensure that families who participate in evaluation or research do not jeopardize their access to or opportunity to benefit from services. Further, real benefits for participation should be made clear and presented to all participants.
- **Research should really benefit children and their families.** There must be a genuine need to investigate the proposed research question and a high likelihood that the study will result in significant findings.
- **Research should not involve deception to the subjects.** Given the unique needs of children with mental health needs, it is critical that deception be avoided. If used, researchers must determine beyond any doubt that there is no alternative way to gather the data and that there is an overwhelming public interest in conducting the research.

List adapted from a chapter in: Hoagwood, K., Jensen, P., & Fisher, C. (1996). *Ethical Issues in Mental Health Research with Children and Adolescents*. Lawrence Erlbaum Associates.



Federation Initiative Promotes Family-Centered Evaluation

Mary McCormack, Dakota Enterprises, Consultant to the Federation

Elaine Slaton, Technical Assistance Coordinator, Federation

The Federation is undertaking an initiative aimed at redefining the ground on which evaluations are conducted. This initiative intends to move the question from “how can we involve families in research?” to “how can researchers be helpful to the evaluations families are conducting?” The goal is for family members to form their own teams into which researchers may be called to consult, instead of children and families being seen only as “subjects” or family members working on research projects controlled by evaluators.

The Rationale for Family-Centered Evaluation

A substantial part of the Federation’s 10-year history has been focused on its evolving emphasis on and definition of family involvement. This evolution has occurred in tandem with the developing field of children’s mental health services. No where can the changes about the ideas of family involvement be seen as clearly as in the conceptualizations around family involvement with services. As the field has moved from ideas about services being family-focused to family-centered and now family-driven, many service programs have recognized that families are the ultimate experts on what they and their children need. The history of the Federation on this topic of family involvement illustrates some of the dynamic elements of family empowerment—that family voice and action lead to ownership of processes like service provision—and now evaluation.

Historically, the traditional research model has limited the knowledge gained by disregarding the expertise of families and of people belonging to cultures about whom research projects have been de-

Family-Centered Evaluation

The family-centered evaluation model recognizes that:

- Families have the most complete knowledge and understanding about their own lives and experiences.
- Families know best which evaluation/research questions should be posed of the world they live in.
- Families know best what information they need to improve the quality of their lives.
- The research model is an effective and useful way to gain knowledge and information.
- Researchers and evaluators have the technical expertise needed to fully execute family centered evaluation.

signed. Typically, in this old model of research:

- Researchers selected the questions and designed the studies.
- Families were seen as “subjects” and as sources of data—nothing more.
- Findings and conclusions were rarely reported to participant families and were held as the sole “property” of the researchers.

The logic of this model, which was based in natural sciences, demanded an objectivity that excluded the view points and interpretations of those who had a personal relationship to the topic being studied.

The scientific field is beginning to recognize the value and richness of viewpoints and interpretations that families bring to the knowledge developed out of research methods. Families and researchers are beginning to move closer to the full partnership we’ve strived for in the services arena.

It was exciting to be part of this evaluation project—it was like going off into new territory. Being one of the first parents to do this gave me a tremendous sense of obligation. I knew I was starting a trend that will continue across the country. As parents we have so much potential!

Statement by a family member who participated in the Federation’s Family-Centered Evaluation Initiative



The Federation's evaluation curriculum recognizes that families are the experts on their lives and on the services they receive. As part of this expertise, families are capable of identifying the research that is most in need of being conducted.

Family-Centered Evaluation (continued from page 3)

About the Federation's Evaluation Initiative

The primary goal of the Federation's initiative is to enhance the usefulness of knowledge gained through research methods to improve the lives of children with mental health issues and their families—by changing the relationship between evaluators and family members. An additional benefit of this initiative is that it aims to provide a platform by which family organizations can begin to apply for research dollars. Equally critical to systems improvements as the inclusion of family voices in services and supports planning, implementation and evaluation is the infrastructure necessary to support that inclusion. It, therefore, makes sense for family organizations to be the recipients of research dollars.

Developing the Evaluation Curriculum

During the past six months, diverse representatives of Federation chapters across the country have been meeting as a workgroup with a research-consultant creating a curriculum that will serve as a foundation for training family members to design and conduct evaluations.

The curriculum focuses on the language and skills necessary for performing program evaluations. It emphasizes basic aspects of evaluation, such as:

- How to formulate and ask questions.
- How to select methods.
- How to collect, manage and interpret data.
- How to disseminate results.

Workgroup members have helped to instill concrete examples of program evaluation questions throughout the curriculum to make the abstract theories clear and relevant.

Separate sections of the curriculum include lists of available resources, including evaluation newsletters, useful software, interesting web sites and helpful conferences. Feedback sheets, included at the end of the workbook, will be used as the basis for future additions and revisions.

The Federation Evaluation Workgroup members are:

- **Pat Baker** and **Sherilyn Rowley** from Utah.
- **Carolyn Cooper** and **Karen Hart** from California.
- **Pamela Martin** from the White Earth Reservation.
- **Aminata Stephens** from New York.
- **Teri Toothman** from West Virginia.
- **Elaine Slaton** from the Federation's national office.
- **Mary McCormack** from Oregon as the researcher consultant.

Training and a Parallel Process for Researchers

Several exciting possibilities are being examined as next steps by the Federation, including certifying family members who complete the training as evaluation specialists. Other potential activities include ongoing training and technical assistance opportunities for families. A parallel process training and certifying researchers "family friendly evaluators" is also being pursued.

How To Get More Information

The Federation plans to make this curriculum available through a series of regional 3-day trainings beginning in early 1999. Watch this newsletter for further information, or contact Elaine Slaton at the national office at 703-684-7710.



Why Families Need To Participate in Research and Evaluation

Barbara Friesan, Director
Portland State University Research and Training Center

After hearing a presentation of research findings that included a section entitled, “impact on the family,” a family member asked the researcher,

Help me understand the value of doing this research. We already know that families are stressed out. What’s the point of this?

Such questions about the rationale for research are common, especially questions about how research and evaluation can contribute to improving the lives of children with emotional, behavioral, or mental disorders and their families. Here I address some of these issues and encourage family members to get involved in research and evaluation efforts.

Why Family Members Should Be Interested in Research and Evaluation

Research and program evaluation can be of vital interest to families in several ways. First, family members can directly use research findings in their work with service providers to help ensure that the best available treatment and support are provided for their children. Armed with information about the effects and side effects of medication, effective approaches for specific disorders—such as Attention Deficit Hyperactivity Disorder (ADHD), or depression—or the outcomes of community-based interventions—such as multi-systemic therapy or supported education—family members are better able to raise questions and make suggestions about services for their children so that the best possible decisions are made.

Family members and family-run organizations can also use research and evaluation findings to support their advocacy

efforts for system and policy change. For example, a study in Oregon documented the practice of requiring families to give up custody of their children in order to obtain costly mental health services. Advocates and families used the research findings in this study to argue their case for a change in the law. Now, the Oregon Family Support Network, a statewide organization of the Federation, and university researchers are working together to evaluate how well this legislation is being implemented.

Another example exists in Maine and Wisconsin where the results of needs assessment research were used successfully by family members and advocates in their push for state legislation mandating comprehensive systems of care.

What It Takes For Family Members To Use Research

To be usable, research findings must be accessible to families. This means both that researchers must write and present in ways that are understandable, and that research and evaluation findings must be available to family members.

Plain language versions of research briefs should be disseminated to family organizations and published in newsletters that families read. These should be available on the Internet and/or on audiotapes, and translated into other languages.

Family members and family-run organizations who want to participate in research and evaluation activities can approach agencies and multi-agency systems, asking to be involved in the evaluation of services. The participation of families in the quality assurance process in managed care is crucial, and a few states—such as Arkansas—mandate such family involvement.

Increasingly, university-based research-

(continued on page 8)

The continuing and informed participation of families is essential to ensure the acceptability, relevance, and responsiveness of research and evaluation efforts.

Barbara Friesan

Currently, family members and family-run organizations are directly involved in the evaluation process in a variety of ways. Families of the F.R.I.E.N.D.S. project in the Bronx, New York, are using their superior capacity to put family members at ease to collect accurate and complete data for the project’s evaluation. In Napa and Sonoma counties (California), family members are central to a study of family perspectives about how well the system of care is working. Family members have worked with a researcher to decide the focus of the study, conduct interviews with family members, youth, and service providers, identify themes and important results, and identify processes and services that need improvement.



Families as Full Research Partners

Marilynn Williams, Director, King County Federation of Families

Ann Vander Stoep, Research Consultant
University of Washington

Robert Jones, Director, Blended Funding Project

The King County Blended Funding Project Evaluation

The Blended Funding Project consolidates mental health, child welfare, and special education funding into a single pool that is available to a team led by the child's family and a care manager. When faced with the task of evaluating the Blended Funding Project, **Marilynn Williams** had a vision—tap the wisdom of system-savvy parents to measure whether the care children were receiving was improving their lives. The result has been an evaluation process that includes family members as equal partners with researchers.

Parents have contributed in many ways—but there are several areas where their participation significantly enhanced the validity of the evaluation. These areas were:

- **Define improvement in the child's functioning.** Typically, professionals in the service systems view indicators of success as school achievement, arrest rate, hospitalizations, and residential placements. However, from the parents' perspective, indicators of success may look very different—for example, the family sharing a peaceful dinner together, or the child riding home on the school bus without incident. Through discussion, outcomes chosen for the evaluation reflected the perspectives of all stakeholders.
- **Select measurement instruments.** Measurement instruments must assess the outcomes accurately, but they also must be family-friendly. Team members waded through stacks of instruments and documentation. Family members pointed out when questions—or entire questionnaires—

were demeaning, offensive, unclear, or pointless.

- **Become trained interviewers.** The team decided that peer interviewers would help the families involved in the Blended Funding Project feel more comfortable participating in the evaluation and sharing their candid views about services. Family members were trained to conduct in-person, in-home interviews.

Family members, researchers, and administrators learned to argue their positions with one another and to make compromises throughout the project. The result is an evaluation that is yielding meaningful knowledge.

How were project staff able to carry out this process? To find out more, we interviewed Marilyn Williams of the King County Federation of Families (KCFF) and her colleague, **Ann Vander Stoep** from the University of Washington.

How did you first get together?

Ann: KCFF asked for the evaluation of the Blended Funding Project. The project director, Bob Jones, wanted to work with KCFF in a collaborative way. He asked me to participate.

Marilynn: KCFF wanted the project to be accountable to families and was very eager to see if it had really made a difference. Based on prior experiences with other evaluations that made little sense to family members, KCFF was very insistent that its members participate fully to ensure that this evaluation produced meaningful and useful information.

Ann: I had been doing research and evaluation around family issues for some time, but in all honesty, I had not truly embraced KCFF's message about family participation until that first meeting. From the very beginning, the family members who participated asked challenging questions of me. As I listened

(continued on page 7)

The bottom line—what made it work—was, without a doubt, that we were all passionately committed to improving the lives of children.

Ann Vander Stoep



Families as Full Research Partners (continued from page 6)

to the concerns, I quickly realized that they made a lot of sense. I recognized from the stories they told that a “pat” research design would generate literally more “garbage” information. As a researcher, I place high value on validity—and these savvy parents were offering me a researcher’s dream. I made a conscious decision at the first meeting—to let this evaluation evolve as a creative and collaborative process. It has not been an easy process, but we did end up with an evaluation that is both scientifically sound and useful to families.

How did you decide what to work on together?

Ann: I had anticipated that family members would serve in an advisory capacity—they would bring ideas and I would design, implement, and interpret the evaluation. I sure was wrong! I found that family members wanted to be involved in every aspect of the design—determining what to measure, what outcomes were meaningful, what instruments to use, how to collect data, how to analyze data, and what to report. We decided that if family members were going to own the evaluation, they had to be involved at every step of the process.

Marilynn: At first, there was a lot of give and take. Many family members started the process with distrust and skepticism. It took a long time to break down the resistances. True collaboration clearly takes time for everyone to grow and learn.

Why were peer interviewers important to the work?

Marilynn: Families know what other families need to say about services—and they also know the barriers to doing this. For example, sometimes the questions asked do not allow the respondent to provide the relevant information. A family member might notice this and rephrase questions or probe further to help the respondent provide a more complete answer. On the other hand, if

a mental health worker is the interviewer, families may not answer truthfully if they fear retaliation. Family members serving as interviewers are not perceived as a threat. The goal is to improve the respondent’s comfort while improving the quality of the data.

Ann: Peer interviewers are also the source of important information about the evaluation process. You might say they are key to evaluating the evaluation! They have keen insights as to whether we are getting the information we need, and what aspects of the evaluation may need to be adjusted to enhance the validity of answers.

How did participants grow and develop throughout the process?

Marilynn: Parents came into this project knowing very little about research—other than their own (and often negative) experiences. In fact, at first they were terrified of research. They struggled

(continued on page 8)

Tips for Families and Researchers

Working together as full research partners requires:

- **Flexibility.** Don’t expect to begin at a point of agreement...everything will be a compromise.
- **Patience.** Don’t expect any meeting to go as expected...family members must tell stories and researchers will insist on sticking to an agenda.
- **Trust.** Don’t expect instant respect. You will be required to prove yourself.
- **Humility.** Don’t take it for granted that you, the parent or Ph.D., are the one with all the answers. Both researchers and parents are both wise and ignorant. You will be reminded daily.
- **A Sense of Adventure.** You’ll be traveling in an alternate universe. Enjoy the ride!

It is important to set the right tone at the beginning of any collaboration. We had several ground norms that were key to our success. They were:

- Listen to each other.
- Be respectful.
- Keep on track and keep connecting everything to what is needed.
- Be persistent. Don’t withdraw if at first it looks hopeless.

Marilynn Williams



Families as Full Research Partners (continued from page 7)

with trying to make their thoughts valid. Throughout the process they learned a tremendous amount of information. They learned how to read and use the language of research.

Ann: The family participants read and studied so much about research that every one of them can teach a course in design. They went from antagonism toward researchers, to admitting they didn't know enough to feel comfortable criticizing the research, to understanding basic research methodology.

What do you recommend to others who might want to engage in collaborative evaluation?

Marilynn: Any time you involve families in anything, be ready for them to tell stories. Researchers and evaluators need to listen and use the stories to help better understand the context for the

evaluation. To the uninitiated, story telling can be perceived as an inefficient use of time. But this needs to be the first item on the agenda, because it is through stories that the true issues at hand emerge.

Ann: It is really important for researchers and families to take all of the time needed to build trust. In fact, there should be a rule right from the start that no one is allowed to walk out. Researchers and families both must be willing to work out differences.

Marilynn: Success doesn't come instantly. Months of sitting around a table sharing perspectives and experiences, preceded the pivotal moments where team members "bought in" to the idea that working together was the best way to improve both the quality of the research and the lives of children and families.

The family members stretched my appreciation of who is vital to the research process. I hope someone will scold me if I ever launch into a research project without a team of people whose lives will be most affected by the research.

Ann Vander Stoep

Why Families Need To Participate in Research (continued from page 5)

ers and evaluators are looking for ways to include family input in projects they are planning, but the degree of collaboration still varies widely. Families and family organizations may find it helpful to initiate collaborative relationships with researchers by asking them to help design and conduct studies around topics of mutual interest.

Families may want to take advantage of existing research training opportunities. Various types and levels of research and evaluation training can help family members gain basic information about research concepts and terms. Once armed with this knowledge and skill, family members can be informed consumers of research, be full research partners, lead program evaluation efforts, and conduct their own research.

Family members can also be part of setting state and national research agendas. They can suggest and review priorities for research and evaluation. Fam-

ily members can make an invaluable contribution to the grant proposal reviews by providing family perspectives on the entire process—from the importance of the research questions to the appropriateness of the proposed methodology and dissemination strategies.

In Conclusion

Research and evaluation efforts can help improve the lives of children and families by providing a source of information for service planning and as support for system and policy change. Individual family members and family organizations may choose different levels of direct research involvement depending on their other priorities. To this end, it is essential that families and family-run organizations continue to support funding for research and evaluation as a means to promote system reform and improve service effectiveness.



Family Members Participate in Large Scale Evaluation

Rolando L. Santiago, Evaluator
Roslyn Holliday Moore, Project Officer
Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, Rockville, Maryland

Minty Rivera, Parent Consultant
Families Reaching in Ever New Directions (FRIENDS) Initiative
Bronx, New York

Family members are part of a growing movement that is making services accountable to the consumers whom they serve. In recent years, family members of children with a serious emotional disturbance have increasingly:

- Participated in the development of individual treatment plans for their children
- Assumed leadership roles on service boards.
- Provided direct services and supports for other children and their families.
- Worked on tasks of evaluating the services that their children receive.

A key component of a services program funded by the federal Center for Mental Health Services in the Mott Haven community of the South Bronx was conducting a program evaluation. The program evaluation had strong participation from families in the community.

Preparing for the Evaluation

Before the evaluation began, the director of evaluation received training and field experience on strategies for including family members in evaluation tasks. Community residents were hired as research assistants to conduct interviews. The research assistants used family empowerment, cultural competence, and family and youth satisfaction surveys. Although many of the original community research assistants did not have children with a serious emotional disturbance, as the number of children

served by the program grew, parents of these children were also hired as research assistants.

Before conducting the interviews, the parent research assistants spent at least two hours training on effective interview techniques and confidentiality protections. The training included interview role plays and discussion on how to resolve practical problems they might face during the interviews. In addition, evaluation staff and experienced parent assistants provided newly hired assistants with strong supervision and mentorship, especially during the first few weeks of interviews. Parent assistants and evaluation staff held regular meetings to review and assign tasks and to build a sense of teamwork.

As responsibilities to collect data increased among the parent research assistants, they were asked to participate in a full-day training session conducted jointly with service provider data collectors. For the training session, parent research assistants received a data collection training manual which was also used to train service provider data collectors.

Reviewing the Surveys

Family members reviewed the appropriateness of the language in questionnaires to ensure sensitivity toward the cultural groups represented in the community. For instance, in a questionnaire designed to measure the degree to which caregivers perceive that spiritual beliefs and spiritual practices are related to their children's mental health, some parents indicated that the word "God" should be changed to "Supreme Being" and the term "religious community" should be modified to "faith community."

Many of the forms used in the evaluation

(continued on page 15)

The partnership between family members and evaluation staff in the FRIENDS Initiative evolved into a richer relationship than the one between a passive respondent and a detached researcher. Family members brought to evaluation activities a perspective that eventually influenced the way data was collected, interpreted, and used.

For more information on the FRIENDS evaluation project, call their main office, at 718-402-3999.



Understanding a Research Study

Al Duchnowski, Deputy Director
Research and Training Center
University of South Florida

As family members take on a larger role in research, they come face-to-face with the challenge of understanding the language of researchers. This is not an easy task, but one that is essential if families and researchers are to work together to ensure that research findings are used more effectively—and ultimately, if family members are to join researchers in conducting research.

The place to begin in understanding the language of research is with how researchers communicate their findings in journals and at conferences. In this article, we will take a brief look at one area of research—quantitative research methods.

The following provides family members with a basic understanding of two of the most commonly used quantitative research approaches. These are:

- Experimental.
- Correlational.

Quantitative Experimental Studies

If you were to look up a definition for quantitative experimental research in a textbook, you might find something like this: Quantitative experimental research studies attempt to use controlled conditions to prove something is the cause of some effect. The basic idea is this—the researcher wants to find out if one thing can cause another thing to happen.

Consider this example: A researcher wants to show that a certain type of therapy (called an **intervention** in research articles) is better than “services as usual.” In other words, the researcher wants to know if the particular therapy will cause children’s behavior to improve. To answer this question, the researcher will undertake the following steps:

1) **Pick the measure of study.** The researcher must define the behavior that the intervention is intended to improve.

Once defined, the researcher selects a method to assess the behavior and behavior change. Typically, researchers use the following types of measurements: Formal observation techniques, interviews, questionnaires, and tests.

2) **Select the children who will be subjects.** This is sometimes called the study sample. In this example, the researcher will select two groups of children who will be the subjects or participants in the study. Children in both groups are as identical as possible—at least in terms of age, gender, racial and cultural backgrounds, family income, and severity of the emotional problem. This matching of subjects in both groups is done to guard against the results of the study being attributed to some factor other than the intervention. The researcher may select the two groups randomly—in random samples, a formal procedure is used to sort the sample into two groups.

The researcher designates one group as the **control group** (or **comparison group**) and one as the **experimental group**. The control group will not receive the intervention, but the experimental group will. This allows the researcher to compare the scores of the two groups and draw conclusions about the effectiveness of the intervention being studied.

3) **Assess the children before conducting the intervention.** Prior to conducting the intervention or treatment—in this case, the therapy—the researcher assesses both groups of children to determine their behavior on the outcome measure. Sometimes, this is called a baseline, because it shows where the subjects are in relation to the outcome measure before any treatment is given. Ideally, both groups are similar on the measurement at this time.

4) **Conduct the intervention.** The intervention is conducted with the children in the experimental group only. The control group is treated just as they would have been if there was no study.

The more families know about the language of research, the better they are able to consume it. As families become familiar with how to read and talk about research, they will be in a better position to join researchers on projects.

Al Duchnowski



Understanding a Research Study (continued from page 10)

5) **Assess the children after the intervention.** After the intervention is concluded, each group is tested again to determine if there is a difference in their scores.

6) **Analyze the scores.** The researcher conducts a statistical analysis that determines if there is a difference between the scores of the two groups. Ideally, the experimental group will have better scores on the outcome measure than the comparison group. If the scores are different, a statistical test is conducted to see if this difference in scores might have happened by chance. Researchers refer to this as the probability that a score is not a result of chance.

Sometimes, you will see the symbol ($p < .05$). This means that in only five out of one hundred occurrences could this result have happened by chance alone. When you see the symbol ($p < .01$) it means that there is only one chance in one hundred that the difference in scores was due solely to chance.

Summary. Unfortunately, there are very few experiments that use control groups in the children's mental health field. The reason? They are expensive and very difficult to arrange.

Thus, many of the studies in our field only evaluate what happens when a particular treatment is given to **one** group of children. For example, let's say that I start a wraparound program for children who have mental health needs. I believe that the program will improve the children's emotional behavior. I assess the children, involve them in the program, and then assess them again after they have participated for some time. Assume that the children's scores on the assessment improve over time. Question: Can we conclude that the program worked? A researcher would answer "no" because we cannot be sure that the improvement is only due to the treatment program. It may be due to other

factors that are naturally occurring in the children's lives. While we may have learned much useful information—that the program can be conducted in a school setting or that families are satisfied—we cannot confirm program effectiveness in this manner.

Quantitative Correlational Studies

Another frequently used type of investigation in the mental health field is a correlational study. These studies do not tell us cause—they tell us whether or not two factors are related to each other.

For example, a group of children are given both an intelligence test and a reading achievement test. A statistical test for correlation is conducted and we find that there is a positive relationship between intelligence and reading scores. This means that as one scores higher on an intelligence test, the greater the probability that the individual will also score higher on the reading test. In this example, we cannot conclude that high intelligence causes high reading scores—only that it is related to them.

Scores also can be negatively related—a high score on one factor is related to a low score on another. An example of this might be the correlation between family income and presence of family health problems—as one's income increases, health problems decrease.

Researchers use the symbol r to signify a correlation. The relationship can range between $+100$ (perfect positive relationship) and -100 (perfect negative relationship).

Conclusion

The more families know about the language of research, the better they are able to consume it. As families become familiar with how to read and talk about research, they will be in a better position to join researchers on projects.

Reading the Study

Both types of quantitative studies are written up in basically the same format:

- **Abstract.** This section provides a brief summary of the project.
- **Introduction and review of the literature.** This section presents the context and rationale for the study.
- **Methodology.** This section includes information about the research question, the subjects, the measure of study and instrumentation, description of the intervention, and the research methodology.
- **Results.** The statistical procedures used to analyze the data are presented.
- **Discussion.** Here the researcher provides an interpretation of the results.
- **Conclusion/Implications.** The researcher suggests next steps for further study.



Mountain State Parents CAN Creates Family Satisfaction Survey

Teri Toothman

When the Office of Behavioral Health introduced **New Directions**—a utilization management approach for West Virginia’s Medicaid System—administrators decided that a satisfaction survey was needed to measure its success. **Helen Snyder**, with the Office of Behavioral Health Services (OBHS), contracted with Mountain State Parents CAN (MSPCAN) to create a family satisfaction survey which could be used to measure success, as well as dissatisfaction with all mental health services.

Teri Toothman put together a team of five parents and two professionals to develop what has become the only family satisfaction survey that is recognized by both providers and the state.

Deciding What To Measure

The team decided to measure not only how good the service was, but also how well parents were treated while seeking out the service. For example, we wanted to ask questions such as:

- Were parents treated differently because we had a medical card?
- Did parents have to travel long distances to receive the services best suited for our children?
- Were parents involved in the treatment planning process from beginning to end?

The family friendly survey consists of twenty-four questions that are very easy to read and understand.

Field Testing the Survey

The survey was piloted in the eastern panhandle of the state using a mail back method and in the Morgantown-Kingwood area using a peer-to-peer approach. We chose a mail back method for the Eastern Panhandle area because

it is rural. Initially, we only received five surveys from the Eastern Panhandle. We gathered seventy-five from the peer-to-peer group.

While the team was reviewing field test results, OBHS asked us to conduct focus groups concerning services that are funded through the Children’s Mental Health Block Grant. We felt this would be a golden opportunity to also ask parents to fill out the surveys. We were able to offer \$10.00 to each parent who filled out a survey, as well as provide mileage, day care, and refreshments. To date, we have held focus groups in five areas of the state and have scheduled an additional three this fall. During the focus groups we were able to gather 100 more surveys. Each family member who assisted in facilitating a focus group and distributing the family satisfaction surveys received a \$100.00 stipend (per focus group).

Extending Our Outreach

We are currently in the process of developing confidentiality forms and information packets to give to each of the fourteen behavioral health centers. At each center the staff will be asked to randomly choose five to ten families each month that we can contact about completing the satisfaction survey. We plan to pay these parents for their participation. We also plan on paying family members to conduct the surveys by phone interviews. If a family does not have a phone, we either will assist them in finding a phone so they can call us on our toll free line or locating a phone where we can call them.

In February, we plan to contract with a researcher, who will work with our families as a partner to analyze the results and develop West Virginia’s first Children’s Mental Health Report Card. For more information, contact Teri Toothman, at 304-233-5399.

Families felt comfortable discussing their concerns with other families. For example, they voiced their concerns in the satisfaction surveys that there was no respite and they felt their children could stay at home if they had a good respite program. The Office of Behavioral Health Services listened and acted on family concerns by appropriating funds for a pilot respite program. Family members (Charleston-Huntington Area) will be at the table helping to develop this respite program. Mountain State Parents CAN will work with these families to develop a satisfaction survey to be used in the program.

This entire process was developed and implemented by families. The message we are sending to our families is that their input is truly needed and necessary for change.

Teri Toothman



Message From the President

Gail B. Daniels

Each year that we grow together provides us with the opportunity to mature and to evolve as an organization. This year, I gained more knowledge and an increased interest in the importance of family involvement in research and evaluation. I have read and listened to people discuss numerous studies—including those conducted by the Research and Training Centers in Portland (OR) and Tampa (FL) and Macro International, Inc., as well as the Fort Bragg Demonstration study, *A Lesson To Learn*, and McCormack's 1997 study, *There is Good News About Systems of Care*.

I had not fully understood the need for having research that truly responds to the needs of families until I read the overview of the State Children's Mental Health Plan (SCHIP) while responding to the unfriendly Welfare Reform Act and the SSI cuts. The SCHIP overview puts an emphasis on mental health services being delivered by hospitals—a practice which, as we know, forms a barrier to community-based services. It also emphasized that some states exclude substance abuse services. As I read the document, I realized that people not familiar with the family movement would come away from reading this document believing that states should make major decisions. And, this at a time when others were showing what "works" should not be equated with state decision making! Families need to be involved in research and evaluation efforts to ensure that our voices are heard.

Using Research To Influence Policy Makers

Over the years, families have brainstormed and strategized, developed blueprints, experimented, implemented ideas, and evaluated a new approach to services. Our

conclusion is that a family-friendly, culturally competent, community-based system of care in a managed care environment provides the greatest potential for success.

Yet, who has listened to us? Many state policy makers do not know that we exist. Many of the policy makers who have listened to us over the years question our position, claiming that we do not have enough "data" to prove the validity and soundness of our statements. We must change this picture.

In order to persuade policy makers that our positions on issues critical to the needs of families are valuable and operative, we must support our statements with statistical data on positive outcomes. This can only be done when families are involved in gathering the facts. Therefore, we must further our focus and participation by stating:

This is what we need—when we get what we need—it works.

Through our own personal family experiences, we have inherent within us the spirit of fellow feeling and an appreciation of family challenges.

Taking the Lead

We should push for grant funding that allows us to cultivate our research skills. Family members are being paid for part- and full-time evaluation-related positions. And, those family members who are working in these positions tell me that they love their jobs! Not only are they relieving the burden of work from service providers, but they are bringing about new outcomes that are family-friendly. They are leading the way in encouraging consumer outreach to youth and families, increasing their participation.

By participating in research and evaluation, we are establishing a greater, united voice.

We can prepare ourselves for research roles by attending educational seminars and training focused on:

- *Developing listening skills.*
- *Fine-tuning our ability to record vital information.*
- *Identifying discriminatory practices.*
- *Protecting information through confidentiality procedures.*



Capitol Connection

Trina Osher, Coordinator of Policy and Research
Federation National Office

As this issue of **Claiming Children** goes to press, Congress is still enjoying its August recess. All of the critical issues we have been following are still to be considered and resolved when Congress reconvenes after Labor Day. These include:

- S. 10 (juvenile justice).
- Attacks on the protections afforded by 1997 amendments to the IDEA.
- Appropriations for a variety of programs that support children and families.
- Reauthorization of SAMHSA.

In addition, there are several pieces of health care legislation that could affect insurance coverage, patient rights, and access to affordable health care for individuals seeking employment to become independent of public assistance.

Members of Congress need to hear what their grass roots constituency thinks about these issues. This is the time to make your voice heard.

Whether individuals or family-run organizations are happy or unhappy with their current Congressional delegation or state legislature, there is only one way to express that opinion and that is to vote. This is an election year with a good number of senate and house seats at stake. Family organizations can play a key role in educating their members and the community at large about how local candidates stand on issues important to children with mental health needs and their families.

Encourage people to register and vote. Tell your membership where and how to register and vote. Recruit volunteers to offer to drive families to their polling place and watch their children while they vote.

Find out where your local candidates stand on the issues that are important to you. Compose a list of straightforward

questions and send it to ALL the candidates. Tell them you plan to disseminate their responses. You can print their responses in your newsletter (or some other publication) and then let your membership decide for themselves who to support.

Research the voting records of local candidates. Identify recent legislation (passed and failed) of importance to your membership. Find out how politicians voted on these and publish this list.

The activities listed above are and should be conducted in an unbiased and non-partisan manner. That is, the position of the organization is not expressed and all candidates for a particular office are included equally, regardless of their position or party affiliation.

Not-for-profit organizations must follow federal rules with respect to lobbying and political activity. Family-run organizations can take a stand on the issues and actively encourage their membership and others to do likewise provided they do not use federal funds for any of these activities.

A good resource to help make sure advocacy work related to elections is done legally is **The Children's Advocates Campaign Strategy Book**. This guide tells how to design strategies to win public support for children's issues in your community. It is a nonpartisan publication that includes coalition building techniques, strategies for reaching candidates and public officials, ways to become involved in your community, and approaches to working with the media. It also includes checklists, legal considerations, and resources. It is available for \$15.00 (or \$12.00 each for orders of 10 or more) from: NACHRI, Publications Department, 401 Wythe Street, Alexandria, VA 22314.

For more information, contact Trina at: tosher@ix.netcom.com. Or contact the Federation's web site: <http://www.ffcmh.org>.

Another good source of information on children's issues is KidsCampaigns, sponsored by the Benton Foundation. They can be reached at 1-888-544-KIDS or on the web at: <http://www.kidscampaigns.org>.



Young People's Voices

Views About Research

Involving families in research and evaluation is the theme of this issue of **Claiming Children**. Following is a young person's views on the topic.

Angela Nelson

As a consumer, I must say, I know very little about research. I decided to do a little research on research. In talking to professionals who have been in the field of caring for people for ten-to-twenty years, I found there is not a lot of input from consumers and ex-consumers in designing the research.

It is very important that we—as consumers and ex-consumers—be there in the beginning, middle, and end of research. We have very valuable information that some researchers do not have. Ex-consumers have been there and consumers are going there.

Research needs to be in a language consumers can read—if I cannot understand the study you have done on my family, what good does the research do me?

Research needs to be done in a timely fashion. In five-to-ten years, families change “big time,” but many times researchers are just finishing their reports.

Editor's Note: This section presents views of young people. We encourage young people who would like to comment on topics of interest, and/or to share artwork or poetry, to contact:

Angela Nelson
Federation Board Member
1641 Farwell
Chicago, IL 60626
(773)465-7461

Or, email Angela c/o the Federation at ffcmh@crosslink.net.

Family Members Participate in Evaluation (continued from page 9)

tion were completed by case managers through interviews with children and families. Parent research assistants reviewed the completed interviews for any missing information. This was part of data quality control procedures.

Serving an Important Role

Family members also participated in other evaluation activities such as entering data into a computer, helping to interpret results of data analyses, and presenting evaluation findings. But there were many other evaluation activities that family members envisioned themselves doing. Some of these activities included:

- Designing surveys and questionnaires.

- Writing outcome measures, conducting qualitative and quantitative data analyses.
- Conceptualizing an entire evaluation of a service program from a family perspective.

The partnership between family members and evaluation staff in the FRIENDS Initiative evolved into a richer relationship than the one between a passive respondent and a detached researcher. Family members brought to evaluation activities a perspective that eventually influenced the way data was collected, interpreted, and used.

The views contained in this article are those of the authors and do not necessarily represent those of the Center for Mental Health Services.

FFCMH National Office Staff

Executive Director

Barbara Huff

Staff

Linda Donahue
Trina Osher
Marion Robinson
Elaine Slaton
Mary Telesford

Board of Directors

President

Gail Daniels, Washington, DC

Vice President

Barbara Sample, Billings, MT

Secretary

Beverly Bell, Richmond, VA

Treasurer

Jane Adams, Topeka, KS

Board Members

Kathleen Berg, Meridian, ID
Lucille Eber, LaGrange, IL
Gene Karp, Arlington, VA
Alan Blankstein, Bloomington, IN
Patti Derr, Conroe, TX
Julie LaMonaca, Billings, MT
Ira Lourie, Rockville, MD
Carmen Pola, Boston, MA
Sue Smith, Atlanta, GA
Amin Valentin, Putnam Valley, NY
Angela Nelson, Chicago, IL
Teri Sanders, Flagstaff, AZ
Teri Toothman, Wheeling, WV

Board Consultants

Barbara Friesan, Portland, OR
Kathy Potter-Dennis, Chicago, IL

Claiming Children is edited and produced by Warger, Eavy & Associates. Address correspondence regarding the newsletter to them at: P.O. Box 3836, Reston, VA 20195. All other correspondence should be sent to the Federation of Families for Children's Mental Health at 1021 Prince Street, Alexandria, VA 22314-2971.

<http://www.ffcmh.org>

The publication is supported through a subcontract with the National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, funded through a cooperative agreement among the Maternal and Child Health Bureau, the Center for Mental Health Services' Child, Adolescent and Family Branch, and the Administration on Children, Youth, and Families.



News and Notes

Don't Forget!

The Federation's Annual Conference is:

*November 19-22, 1998
J.W. Marriott Hotel
Washington, DC*

For information, contact

*B-C Family Productions
16 Sagamore Place
Hillsborough, NC 27278
Phone: 919-477-3677
FAX: 919-479-5247*

Federation Staff Move On

During August, both **Pedro Briones** and **Pat Spain** left the Federation's national office staff. Pedro has joined the Washington, DC office of Congressman Pete Stark (CA) and Pat has returned to Mississippi. We will miss both of them and wish them well.

Mountain State Parents CAN Receives Award

Mountain State Parents CAN received the **People's Choice Award** at the WV Family's First Annual Family Conference this past spring. The award was presented by the Governor's Cabinet on Children and Families. Award winners are nominated by families in the field. Nominees had to demonstrate that they use family-centered practices in their work. Mountain State Parents CAN is the WV State Organization for the Federation.

New Resources

Early Warning, Timely Response: A Guide to Safe Schools. This 40 page document presents a brief summary of the research on violence prevention and intervention and crisis response in schools. It tells school communities what to look for and what to do. It is available from the U.S. Department of Education and can be downloaded at: <http://www.ed.gov/offices/OSERS/OSEP/earlywrn.html>. Or call: 1-877-4ED-PUBS.

Promoting Cultural Competence in Children's Mental Health Services. This book, edited by M. Hernandez and M. Isaacs, addresses the implications and applications of cultural competence to key areas. **Mary Telesford**, the Federation's Coordinator for Training, contributed to one of the chapters. It is available from Paul H. Brooks Publishers, P.O. Box 10624, Baltimore, MD 21285-0624.

FEDERATION OF FAMILIES
FOR CHILDREN'S MENTAL HEALTH

1021 Prince St. • Alexandria, VA 22314-2971